

MAKING DYING BETTER:
Envisioning a Meaningful Death by Contemplating the Assisted Death

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Abstract

The contemporary juridico-political and bioethical debate over physician assisted dying has emerged as one of the most divisive of the late 20th and early 21st centuries. Commonly strained through Western conceptions of individual rights and near ubiquitous calls for the respect an abstractly defined human dignity, popular discourse on assisted dying tends to promote universal understandings of both human beings as well as ethical, legal, moral action. This thesis, however, holds these debates in abeyance preferring rather to explore the ways in which the possibility of an assisted death creates a more meaningful dying space for many Canadian advocates. And though I cannot answer for everyone, for many of the 24 individuals I spent months interviewing, “hanging out” with and generally following around to various meetings/training sessions, the assisted death is not some nihilistic response to the suffering of our materially bounded/feeling bodies, but a contemporary recurrence of a deeply spiritual, relational and artful dying.

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Prologue

“And what about you, Elijah (my middle name)? Why are you here today?”

Wanda’s words shock me. For at least a few minutes now she has been going around the small conference room asking each of the 25 participants at today’s Dying with Dignity member intensive training, why we are there. A familiar lump appears in my throat. Sweat spontaneously drenches my armpits. Caged, my heart attempts to break free. Agitated, the butterflies brush at the walls of my stomach.

Why was I there? Well, I’m an anthropologist – this is what I do. I involve myself in the midst of other people’s lives. I become part of what’s going on. And that could have been my response, but it would have been a partial truth. There is another reason why I am there – I am interested in death. Well, at least in the way that others navigate death’s reality.

In that moment I feel my brother’s body bearing down upon my chest. I hear him crying. My sister joins our pile. And then my father. Startled from sleep I am aware that something has happened.

<scene>

Somehow, I’ve arrived in mom’s room. Perhaps I’m sitting in a chair next to her ... maybe I’m standing over her only to wind up in the chair momentarily. Her skin is pallid, yellow and cold. Fortunately, her eyes are closed, but her mouth is slightly agape. Parched lips. The large brown Lazyboy swallows her body. Head tilted ever so slightly to the right. I probably never did this, but I feel myself tracing the decades old remnants of a measles inoculation on her left arm. What happened?

<scene>

Jeff Farrow, her physician and a family friend, attempts to comfort and wraps his body around my shoulders. We are huddled together on the scratchy brown, green and white living room couch. I feel a thick mess of hair from what must be his massive right forearm resting on the nape of my neck. We are facing the persistently out of tune piano that I used to know how to play. The brass lamp with its green glass shade sits hushed on the piano lid. There are no lights on in the living room. Back in her room, my dad and the morticians must be doing their job. Timeline-ing. Picking up her body. Moving her limbs. Placing her on a stretcher.

<scene>

“I hate you!” I’m pretty sure that’s verbatim. She reclines across the second brown couch – this one perfectly positioned beneath the three large windows – as if the honored guest at some Roman nobility’s dinner party. (I’m pretty sure this is the same couch mom sat on twelve years

ago when I saw my new sister for the first time). I think she was on her left side, but it could have just as easily been her right. I'd seen her sit like this hundreds of times on those early school day mornings as I shuffled across the hall to shower. She would have already been up for hours—praying, reading the Bible, and meditating (and quite possibly napping). That night though, the fury of my words reverberate. She looks at me with that pixie cut that we have all finally become adjusted to. She was always beautiful. I know this isn't what she was wearing, but I place her in that ribbed, white tank-top and those faded black jeans she used to wear. Lady Di in all her priceless gowns could never compare. Her hazel eyes piercing and hurt – I'm not allowed to see my girlfriend when I return from Washington D.C. We lied to my parents and had met in secret – under their roof, this was strictly forbidden. I rush to my room and wanting to slam the door, but knowing that would only make matters worse, I settle for banging the drawers of my chest of drawers as I finish packing for the four-day trip.

<scene>

Matt Lyons, a classmate of mine, is playing with his food. We are at a seafood restaurant somewhere in Washington's suburbia. He has arranged the crab-less legs on his fingers. I hate seafood. It was probably Dr. White who tapped me on the shoulder and asked if I could come outside for a moment. Somebody, presumably Cheryl Farrow (the physician's wife), tells me that mom is no longer doing well. My dad wants me to come home tonight. Steven, the bus driver, tells me that he is sorry as I step on our bus to grab my backpack. Why do I remember his name? Jeff Farrow hails a taxi and rides with me to Dulles. He buys our tickets. We must have waited to board, but all I can remember is sitting on the flight eyes glaring out into the pitch-black night only to occasionally be met by passing spots of light. Empty. Shredded heart. What is going on?

<scene>

My brother is home from university. She is in their bedroom. She's in the large brown Lazyboy. It seems to swallow her. I'm allowed to be alone with her. Tears burn. I am sorry. I beg forgiveness. I love you. I do not hate you. Nothing. Holding her hand. Weeping. She cannot speak. She cannot move.

<scene>

We periodically paint her tongue with a moist brush. Sometimes we use ice or frozen Keva Juice instead. Lately, she has craved Keva Juice ... one of the orange ones I think. Friends gather. We sing hymns. We pray. What about, I cannot remember. Was it for healing?

<scene>

The hours of "thank you for coming"-s have ended. My white button-up is smeared with the remnants of the overly made-up. I will never wear this shirt again. Hundreds of "there's a purpose to all of this"-s, "everything will be alright"-s, "if there's anything you need just let me

know”-s “I love you”-s “we love you”-s – well intentioned every one. People loved her. They must not know what I told her that one night.

<scene>

We drive slowly by the Ingles on 11-E. Rank and file, the others follow. Gloomy day. There’s a small tent at the burial site. My family and a select few sit as our pastor, Mark Harrod, says stuff over her casket. She’s being buried next to an old friend of hers – he had tried to kill her once (at least that’s how I’ve always remembered the story). She and my father had been a rock for him. Crippled form, drug addled mind, they were always there. When he died, they arranged for his body to be brought back the Jonesborough from podunk Kentucky (or was it Virginia?). Somehow fitting. Selfless love. Lingering guilt. The car door closes ... *Tetelestai* – is it finished?

<scene>

Back in the conference room, with the others’ eyes staring into me, I repeat some version of this story.

Introduction

Case in Point

As photos from Brittany Maynard's wedding fade across my computer screen, their vitality and energy crash inelegantly against her voice's somber drone as it recounts the brief timeline from abnormally aggressive headache to terminal brain cancer diagnosis. Following a series of unfamiliar and debilitating headaches, on January 1, 2014 Brittany's physicians diagnosed her with Astrocytoma Grade II and offered anywhere between three and ten years of life. While this prognosis left her with several years to live, "when you're 29-years-old, being told you have that kind of timeline still feels like you're being told you're going to die tomorrow." Within months the diagnosis worsened to the "most aggressive form of cancer," glioblastoma multiforme. New diagnosis, new prognosis – six months. Save the miracle so desperately hoped for, she was told nothing could reverse this reality. As we continue watching, we are confronted with a black screen and white letters – "Faced with very few options in her home state of California, Brittany and her family chose to move to Oregon so she could access its death-with-dignity law. She met the criteria, and received a prescription for medication that will end her life peacefully and painlessly, if she chooses to ingest it." The chosen date? November 1, 2014 – coincidentally my mother's ten-year death anniversary.

As I watch this video for what must be the fiftieth time, I am well aware of what will happen in the following scene. The camera tightens around Brittany's hands. She reaches into a slender, yellow leather clutch and, without fumbling, retrieves two orange-*ish* prescription bottles. Presumably, these bottles contain the 100 capsules of legally prescribed secobarbital that will be used to end her life. Her voice says "I don't look at it every day ... [but] I know it's there when I

need it. ... I plan to be surrounded by my immediate family, which is my husband and my mother and my stepfather, and my best friend who's also a physician. ... I will die upstairs in my bedroom that I share with my husband ... [and] pass peacefully with some music that I like in the background." From what I have read elsewhere (Egan 2014), I also know that each individual capsule needs to be broken apart to free the powder inside. Mixed with water, her lethal cocktail will be complete. Death will occur. Rocked by this realization, I am left wondering how those moments tearing the pills apart passed: solemn silence? Loving conversation? Cartel jokes? Where did they sit? Did they dump the minute contents of each capsule into tidy white piles or a central pot? Whatever the case, it must have been difficult. If the decision had not felt real before, it must have felt very real then.

Brittany's decision to end her life reignited the embers of the American debate on the right to die. While much of the media either attempted to remain neutral or supportive, several columnists, guest writers, bloggers and television personalities spoke out at the travesty of her decision to access an assisted death. Open letters like Kara Tippetts' (2014), a mother of four with cancer that has metastasized from her breasts to her entire body, drew on religious foundations while asking Brittany to reconsider:

Your life matters, your story matters, and your suffering matters. ... [Y]ou have been told a lie. A horrible lie, that your dying will not be beautiful. ... *[T]he lie* that suffering is a mistake, that dying isn't to be braved, that choosing our death is the courageous story. *No* – hastening death was never what God intended. ... *[B]eauty will meet us in that last breath.*

Citing Tippetts, New York Times op-ed columnist Ross Douthat (2014) called for a "case for the worth of what can seem like pointless suffering [to] be made either without [a] theological perspective, or by a liberalism more open to metaphysical arguments than the left is today."

Operating on the assumption that religiously oriented messages such as Tippetts' would hardly touch the secular masses, Douhat calls for an understanding of human life not tied to materialistic concerns less "many more tragic stories will have the ending Brittany Maynard has chosen to embrace." From these perspectives, Brittany has become a victim of the lie that suffering is a mistake. A victim of the lie that her life does not matter. A tragic ending. But is it not possible that Brittany and her loved ones truly believed an assisted death constituted the most meaningful option?

Setting the Stage

This thesis is about the contemporary problems of death and dying. In the 1970s and 80s, historian Philippe Ariès told us that in Europe and North America modern death had become invisible – something "shameful and forbidden" to see (1974b, 85). Whereas death had once occurred within the presence of the public, Ariès traced the way in which it had slowly receded from this privileged position. Demonstrative of this fading presence, Ariès cites the exponential realignment for place of death from home to hospital and resultant severance of dying persons from community relationships. In Canada alone, deaths occurring within a hospital rose from 50.9 percent in 1950 to 80.5 percent in 1994 (Wilson et al., 2001). Rather than being surrounded by loved ones, dying people now faced solitary interactions with nurses and physicians attending to numerous "patients" simultaneously. Furthermore, perhaps exacerbated by a growing sense of unease (even disdain for some) regarding the possibility of an afterlife, an increased hesitancy to inform or accept the dying-ness of the dying person similarly encouraged this concealment. This reluctance to speak openly about the dying process made "everyone [an] accomplice to a lie born of this moment which later grows to such proportions that death is driven into secrecy" (Ariès

1981, 562). The sociologists Mellor and Shilling have gone so far as to write that “modern society is, in the last resort, people standing *alone* in the face of death” (1993, 427). Thus, hidden beneath these shrouds, death had become fearful, taboo, and a failure to be fought.

By contrast, Ariès juxtaposed this denied death against the ancient form of “tame” death. Couched within conceptions of an afterlife of peaceful repose, within the tame death, the individual dying (or recently dead) person was subordinated to the “past and future of the species” (1981, 603) thus making death “not a personal drama but an ordeal for the community, which was responsible for maintaining the continuity of the race” (ibid.). Arousing neither fear nor awe, this frequent and acknowledged death offered something more than death to the dying person. Modern death had become wild and could offer nothing but fear to the dying person.

But when Cicely Saunders spearheaded the opening of the world’s first modern hospice in 1967, she and her colleagues at St. Christopher’s in London institutionalized an (re)emergent concern for making modern dying better (Clark 2007). Without denying death’s imminence, Saunders and the resultant hospice movement sought to alleviate the physical pain of dying individuals. Elsewhere, the psychiatrist Elizabeth Kubler-Ross sought to extend Saunders’ end-of-life care past material concerns and on into the existential anxieties often associated with dying. To do this, she called on those surrounding the death bed to focus on the “patient as a human being, to include him in our dialogues” so as to learn from him “more about the final stages of life with all its anxieties, fears, and hopes” (2009, xxiii). Her subsequent delineation of these final stages offered the therapist greater attunement to the dying person’s special needs that could be fulfilled by simply taking the time to “sit and listen and find out what they are” (ibid., 219). Similar to Ariès, Kubler-Ross believed that part of the existential angst surrounding the end-of-life was the unfortunate by-product of hemming off dying person from their dying-ness. If invited back into

this conversational space with their physicians, therapists and loved ones it would be possible discover the source of their angst and alleviate it with subsequent treatment.

While palliative care options and the modern hospice movement have established histories and received numerous commendations here in Canada since the early 1970s, the immensity of public debate surrounding high profile court cases on assisted dying¹ (i.e. Sue Rodriguez 1993-1994 and Gloria Taylor, et al. 2013-2015) demonstrate a continued, if not pervasive, dissatisfaction with contemporary forms of dying in Canada. This is not to say that proponents of assisted dying are seeking the complete abdication of hospice and palliative care, but rather that they are concerned with the inability of these forms to fully address that “suffering only death can end” (Dying with Dignity 2015b). For these individuals, though Kubler-Ross’ contribution to the hospice movement is indeed built around the existential concerns of the dying person, there are times when hospice care can only scratch the surface of suffering without full rectification. By utilizing terms such as interminable and irremediable suffering, they portend certain forms of suffering as untouchable and even unintelligible.

Nonetheless, much of the literature on assisted dying continues to search for the “what” (physical, mental, existential, etc.) of this suffering. Perhaps it is assumed that if the “what” is uncovered, then something can be done to alleviate this suffering. Though not wrong to do so, by placing suffering – and even death, dying or living – within the strictures of “what” questions, they become relegated to intransitive facts of the actual. They can do nothing aside from form sets of

¹ Here it is important to point out that there are two similar, yet distinct models of assisted dying being sought within the Canadian context – physician assisted suicide and active euthanasia. While both involve a physician’s approval and an individual’s direct request *and* consent, assisted suicide requires the individual to ingest the physician prescribed pharmaceuticals themselves. In euthanasia, however, the physician directly administers a lethal dosage of the life-ending drugs. Though the province of Quebec has taken up euthanasia as their preferred model, as suicide was decriminalized in Canada over forty years ago, before it’s legalization in February 2015, many right to die activists point to the illegality of physician-assisted suicide as discriminatory. For this reason, I focus primarily on assisted suicide, though euthanasia also made up a part of my conversations.

statistical data sitting passively on some page. And there are times when this is both important and needed. But what if, as the anthropologist Lisa Stevenson says, “sometimes it is the truth of the possible as opposed to the actual that needs to be conveyed” (2007, 14). As such, rather than focusing on the *what* of suffering, we will be pursuing *how* the proponents of the assisted death seek to restore/create meaning throughout the dying process – how contemplating the assisted death contains the potential for the good death.

Ranging from tangentially interested hospice care counsellors to the outgoing CEO of Canada’s largest right to die organization, Dying with Dignity, and the former Conservative MP “leading the charge” in Parliament, as humans contemplating what it means to be alive, dead or somewhere along the way, each play a vital role in our inquiry into assisted dying. Though several were uninterested in taking up as part of their daily life the subject position of “activist” for assisted dying, by simply signing petitions for legalization, spending a few hours with an anthropologist interested in their perspectives or picketing in front of the Supreme Court, all play some role in its continued emergence. And while the assisted dying movement neither originated nor exists solely within the confines of Canadian geography, this thesis remains somewhat within these politically developed boundaries and is centered around those whom identify as Canadian. That being said, the individuals I spent time with hardly live in bubbles and several (including myself) draw on examples from other locals such as the US, Netherlands, Belgium, Switzerland, the UK and Australia. Conducted over seven months in 2015, this thesis derives from a series of semi-formal to informal interviews with 24 individuals and several Dying with Dignity training sessions and meetings as well as one town hall meeting in Toronto.

From such a perspective, this ethnographic research sheds light on meaning making among those fighting for assisted dying. It shows how the story of assisted dying can be about more than

a mere reductionism of life to materialistic determinations as is so often portrayed in critiques like Tippetts' or Douhat's seen above. Often attributed as the culmination of a self-serving individualism brought on by increased secularization, this thesis contests these claims by revealing undercurrents of deep seated concern for others in "my" dying as well as conceptions of spiritual continuity, connection and transformation. But I am getting ahead of myself. For now, we should trace out the problem at hand a bit further. To do this, Brittany's story touched on above will be tied into other literature as we work out the specific problematic of concern for this thesis. Following this, of course, there will be a brief introduction to the conceptual framework and methodological pathways weaving throughout the resultant ethnography.

Is an Assisted Death a "Good Death"?

With the expansion of hospice and palliative care throughout the late 20th and early 21st century in Western Europe and North America, the (re)burgeoning concern for the "good" or "better" death found itself front and center within (bio)ethical, biomedical, legal and socio-political debate. Concerned with what does or does not constitute a good death and their moral permissibility, one of the most radical options to (re)emerge from these debates was that of assisted dying and what it represents, symbolizes and involves. Figured by some proponents as the pinnacle of human freedom – "if we are free people at all, then we must be free to choose the manner of our death" (McLellan 2011) – assisted dying presumably offers individuals control over the creation and implementation of their own version of the good death. Whereas hospice and palliative care remain somewhat within the confines of a procedural death (i.e. time frames and medications to be enacted throughout the dying process), the assisted death is often visualized by my informants as free of these constraints and reliant purely upon individual desire.

Though it should be noted that this debate has roots much deeper than mid 20th century (Lavi 2007), like so many others, the ethicist and philosopher Margaret Somerville questions how the assisted death has become such a prominent concern over the past sixty years. By placing the impetus on the “profound changes in our postmodern, secular, Western, democratic societies” (2001, 108), Somerville cites an “intense individualism,” paired with an empty ethic of materialism and lost sense of mystery as influential factors in the contemporary interest with assisted dying. Of course, as we’ve seen in Brittany’s case, these critiques are not unique to Somerville, but rather key into a particular criticism of modernity (Somerville uses the terminology of postmodernity) prevalent within the opposition to assisted dying. Chock full of allusion to spiritual and societal concerns, these accounts repeatedly call for the resurgence of the transcendent value of human life. The philosopher Charles Taylor captures this sentiment when he defines modernity as “that historically unprecedented amalgam of new practices and institutional forms (science, technology, industrial production, urbanization), or new ways of living (individualism, secularization, instrumental rationality); and of new forms of malaise (alienation, meaninglessness, a sense of impending social dissolution)” (Taylor 2004,1). Whether deriving from within religious conceptions of God-given value or some form of Kantian humanism, it is generally understood that modernity’s movement toward materialism inhibits the end-of-life from being seen as valuable. If there is no built in, intrinsic value to human life, assisted dying easily takes up position as a quick exit from a worthless existence. Individualism, secularization, alienation, meaninglessness – this is our predicament.

But what is striking about these complaints is the way in which they are similarly taken up by several proponents of assisted dying. That assisted dying advocates also call out intensive individualism and losses of transcendent connection complicates this picture of assisted dying as

subsumed within the meaninglessness of modernity's materialism. Furthermore, rather than simply complicating the issue, these advocates even leave open the possibility for assisted dying as a corrective measure to these problems. While the point of this thesis is to show how assisted dying might be seen as creating the space for a meaningful and good death in tune to collective concern and transcendent spirituality, we will start by looking into how opponents and proponents similarly take on individualism and secularism.

First, let us look at individualism. Somerville's concern is that our "intense individualism ... can undermine the intangible infrastructure on which society rests, the communal and cultural fabric. [And] individualism untempered by concern and recognition of a duty to protect and promote community will inevitably result in destruction of the community" (2001, 108). In other words, society relies on both shared cultural values and deep networks of connection between individuals to function properly. Once these foundational concerns are weakened the entire community structure begins to founder and eventually collapse. And in light of this thesis interest in death, if left unchecked, individualism has the capacity to sever connections between dying person and community bringing about deleterious consequences. Even though assisted dying is often championed under the guise of personal autonomy, Somerville pictures it as slowly removing a sense of responsibility toward others within society. Once this dissociation from communal existence has happened, it becomes possible to see the dying person as burden (to society or to family). In this "slippery slope" scenario, there is a reversal (or at least alteration) of the desired outcome. Whereas the quest for assisted death began as empowered choice, it would inevitably morph into imposed judgment on the burdensome dying person. From empowered to vulnerable.

Somerville's emphasis on the importance of individual choice for proponents of assisted dying is not unfounded. As the chapter president of Dying with Dignity Ottawa, Sarah, told me,

assisted dying is a burgeoning concern for “individuals who feel that we should have control over our bodies and with that control over when and how we die – especially in circumstances that involve immanent death and substantial suffering.” A simple scan of recent articles or blogpost will demonstrate further how public discourse on assisted dying is replete with calls for individual choice. So yes, personal autonomy and individualism are readily embraced among proponents of assisted dying. But what Somerville and others seem to overlook is the way in which family and community are often invoked in parallel to these calls for autonomy. In this way, does being an advocate necessitate a wholesale devotion to such intense individualism?

The second point of interest is the way in which Somerville and others often characterize assisted dying as the consequence of an increasingly materialistic society that has lost its sense of wonder with human life. She equates this to a loss of what she and others have called the “secular sacred.” Without even an inkling of the secular sacred, there’s the possibility that “wornout people may be equated with wornout products; both can then be seen primarily as ‘disposal’ problems” (2001,113). Similarly, our society is opposed to mystery. There is nothing that should be left within the realm of mystery. We simply convert mystery into problem and if this is done then we are in need of a solution – why not let euthanasia be this solution?

What Somerville advocates in the stead of this focus on individualism and to replace the lost sense of mystery is the creation of a secular language that accounts for the “human spirit” – the “deeply intuitive sense of relatedness or connectedness to the world and the universe in which we live” (2001, xiv). As death and dying have traditionally served as points of reference for the valuation and meaningfulness of human life, it is vital that we establish a new paradigm accounting for this human spirit rather than accept the nihilism associated with the assisted death. This entails the creation of a “metaphorical-metaphysical space within which we [can] hope to encounter

[death]” and the renewal of our lost sense of “belonging to a community” (2001, xv). But disconnected and disenchanting, our fear of death prevents us from re-establishing this connection with the community and experiencing the accompanying transcendence. Though offered up as the “good death,” the assisted death fails to deliver. In order to truly experience the good death, “we must be able to experience belonging to something bigger than ourselves; a sense of hope – a connection with future; and a sense that we are loved and can love in return” (ibid.).

But advocates of assisted dying believe that they are similarly acting to create this space. While Maynard ultimately fell well within her legal rights as an Oregon resident, the opposition with which this decision was met demonstrates the continuation of this debate over legality and ethicality in the United States. Similarly, though the Supreme Court of Canada decided on February 6, 2015 to decriminalize physician assisted suicide for terminally ill individuals and allowed Parliament exactly one year with which to create legislation, stalling on the part of the federal government has recently forced a four-month extension to June 6, 2016. Furthermore, the Conservative government’s efforts to engage the public on the issue consisted in creating a three-member “expert panel” including two outspoken opponents of physician assisted dying. Stacking the panel in such a way prompted Wanda Morris, CEO of Canadian right to die organization Dying with Dignity, to question the government’s motives suggesting that “the government simply wants this issue to go away” (Dying with Dignity 2015a).

Wanda’s indictment of the federal government closely resembles historian Philippe Ariès’ suggestion that we moderns (at least those of us living Western Europe and North America) approach death by *fighting* for life (1974a, 1974b and 1981). But what does Ariès’ *fighting* and snubbing of death or the federal government’s treatment of assisted death as nuisance mean for those who have physically, mentally and perhaps emotionally deteriorated to a point where life

has become, in their assessment, unlivable? By resisting the urge to fight for life at all costs, individuals seeking legal authorization to attain a physician assisted death are raising a multiplicity of moral and ethical questions challenging contemporary norms of life and death. We will take John as an example. John and I met at the training session fronted by Dying with Dignity and led by Wanda Morris mentioned in the Prologue. Following our initial meeting, I spent a couple of days in Brockville with John and his wife. Somewhere in our conversations I ask him what is so important about the right to die movement for him:

So many people, in my impression, live to keep living. ... Not many people seem to want to talk about [death] until they're told that they're terminal. And yet the reality is that they were terminal on the day they were born. ... [There are a number of] variables in the grand scheme of things, but the fact is that I will die and I have to deal with that. I'm presented with that right now! Right now, I know I'm going to die. I don't know what the circumstances are going to be at that time, but I can think about it.

For Ariès, Wanda, John, and a number of other advocates within the physician assisted death movement, death's willed invisibility and people's living just to keep living is problematic. And that is what this thesis is about. Certain uncertainties and known unknowables. The contingencies of desire and resolve. Paradoxes. The when-s and how-s known to exist, but unknown in their when or how. The cornucopia of compatibly incompatible rights – right to die, right to control, right to do, right to (not) die, right to (not) control, right to (not) do. As well as the implicated what if-s of previous lives. All in all, this thesis is about the ways in which access to an assisted death could be perceived as providing a meaningful space for dying.

Literature Review

Assisted Dying

Literature and public debate focused on assisted dying predominately fall within two categories – abstract juridico-ethical discourse (Battin 1982; Gorsuch 2006; Keown 1995; Raus, Stercyx and Mortier 2011; Sommerville 2001; Young 2007) or qualitative/individualized research on “why” it is desired or not (Chapple et al. 2006; Fadem, Minkler and Perry 2003; Hendry et al. 2012; Lavery, et al. 2001; Pearlman, et al. 2005; Wilson, et al. 2000). Philosophical, ethical and legal literature on assisted death often contributes to the creation of pathways (Emanuel 1998) along which the individual moves forward, backward or not at all. However, primarily concerned with rationally analyzing questions of “whether or not” (i.e. assisted dying is ethical or has legal precedent; individuals should be allowed to access an assisted death; etc.), this literature often fails to take the humanness of the individuals behind requests into account as ethnographic research in anthropology is prone to do. Riveted to the ways in which logical reasoning creates knowledge, these arguments typically work through syllogistic processes of “because A, and because B, then C must be”

Take, for example, philosopher Robert Young (2007) who aligns himself along two fronts of debate while arguing for the moral permissibility of medically assisted death: respect for the autonomy of the sufferer, and compassion for the sufferer. As he traces out his argument, there is a clear logical progression with each point hinging on the last. He argues that development and implementation of extreme life-extending biomedical technologies has created a space of uncertainty where there can be no objectively correct path to follow. Without a predetermined path, the patient’s autonomous decision making must be respected. As autonomous decision making should be “consistent with other important values we hold” (Dworkin 1988, 21) based on

previous life experience, one's decision of whether or not to access an assisted death carries the "greatest [moral] weight" (Young 2007, 23). One, two, three – one's autonomous desire must be respected. Similarly, in his second point he argues that though biomedical technology has become increasingly powerful, there are times when interventions no longer produce positive outcomes. When intervention becomes futile, as is in the case of advanced stages of Amyotrophic Lateral Sclerosis, suffering is both prolonged and pointless. At this point, the compassionate thing to do would be to follow the autonomous decision making of the dying person (Young 2007. 24). Though Young's arguments are clear and agreeable, they neglect the experience of the individual seeking out such an intervention.

Nonetheless, these overarching and abstract debates on the legal and ethical components of assisted dying, though undoubtedly important for working through the issue, are not the focus of this thesis. Logic, reason and rationality are not always necessary aspects for the desired access to an assisted death. When I asked Barbara, a retired social worker in her 60s, whether or not rational decision making was necessary for assisted dying to be accepted fully she unhesitatingly answered:

Ohhhh no! Listen, I come from a social work, a study of human nature, a woman and her person in her profession who studies human nature – there's no way that all our decisions are rational. We bring baggage. We do things that are stupid, that have nothing to do with what's even in in our best interest. What do I think – when the time comes I have to make those decisions that I'll make a rational decision? No! I think some of it will be – and is it important? No! It's not important that it be rational. And what's rational for you may not be rational form me. If I'm totally basing my argument on I'm trying to save money for my kids so that they will inherit a lot, I'll make one decision. If I'm trying to make decisions about ... what kind of memories I want to be carried on of me, with my grandchildren and my great grandchildren, I'll make other kinds of decisions.

So perhaps it is less about requiring a logical rationality, because what this means changes from person to person, and more about a desire to remain open to irrational decision making. Thus, guiding my work was the primary research question: *How does the possibility of an assisted death*

open the space for a more meaningful relationship with the dual processes of death and dying for advocates? There is some precedent for this – research on assisted death has not solely focused on the legality or ethicality for society writ large. There have also been studies that have attempted to hone in on the individual and their perceptions toward and desires for an assisted death whether they arise out of a concern for lack of adequate palliative care (Sullivan et al. 2000; Foley 1997), feelings of hopelessness or depression (Ganzini 1998; Breitbart et al. 2000) or concerns toward perceived losses of control, functionality or even senses of one’s own self (Lavery et al. 2001; Back et al. 1996).

However, much of the work done on this front has served as a means to an end – a way of redirecting the conversation back toward the moral debate of the practice. Emanuel et al. (1996) spent months interviewing over 700 individuals from the general public and oncology wards (patients and physicians) on their thoughts toward assisted death. The responses indicated a majority of oncology patients and members of the general public found assisted death an acceptable response to unremitting pain in terminal cases. In an interesting twist, oncology patients living through extreme pain were less likely to find assisted deaths acceptable whereas individuals labeled as “depressed” were more likely. Armed with this knowledge, the authors set forth with the admonishment that individuals requesting an intervention should be evaluated for depression or deep psychological distress and, if necessary, treated for such ailments.

Cristina Monforte-Royo and her colleagues (2011) have recently set out to explore the ways in which the “wish to hasten death” has been an object of analysis in European and North American clinical studies. Though the exact meaning behind the terminology of the “wish to hasten death” proves to be a bit elusive (i.e. are we talking about terminal sedation, voluntary stopping of eating and drinking or their less accepted counterparts of assisted suicide and euthanasia), their

paper reveals a series of research projects focused unequivocally on scientific forms of “knowing” why someone would be interested in an assisted death. As if the intricacies and uncertainties of desire could be measured and analysed. They point to the development and utilization of the methodological instrument of the Desire for Death Rating Scale (DDRS) (Chocinov et al. 1995). Presumably, the DDRS allows interested parties to validate the level of sincerity with which an individual actually desires to end their life. Another group of psychiatrists headed by Barry Rosenfeld (1999) established an alternative tool for the measurement of death desire by way of the Schedule of Attitudes towards Hastened Death (SAHD). Similar to the DDRS, the SAHD attempts to accurately identify the tenacity of an individual’s desire to die based upon a series of 20 true/false questions.

In an extensive literature review of sorts, Rosenfeld attempts to lay out a “summary of what we know and what we do not know” (2004, 175) about the motivations guiding people to request an assisted death. Drawing upon numerous studies focused on the “hastened death,” he challenges the common assumption that alleviation of physical pain lies as the central desire for an assisted death (*ibid.*, 96). Rather, in his pursuit to scientifically ground our understanding of why assisted deaths are pursued, he develops an argument for the “central role played by depression and psychosocial factors” (165). Typically, this would be the point where we assume that he somehow believes this desire to be the result of some pathological disorder, however, he affirms that depression does not always equal irrational (123). Thus what rises to the fore of importance when considering how to guide clinical practice or create comprehensive social policy regarding assisted dying lies within the identification of when the ability to think rationally disappears – what determines one’s competence (167). As such mental health professionals should be at the forefront of research on and communication with those who are thinking through the possibility of an

assisted death (174). Studying the reasoning in this sense serves more as a means to an end rather than an end in and of itself.

Nonetheless, couched within the terminology of “dignity,” these arguments for autonomy and compassion hold a prominent position within public discourse of the Canadian right to die movement. However, anthropologists Gandsman and Burnier (2014) recently identified the poor performativity of “dignity talk” within the debate as both sides tend to take on the concept though from divergent perspectives. Those advocating for the right to die tend to utilize the term as a way of tapping into the extreme individuality with which each of us approach our deaths. Though our deathbeds may be surrounded by friends and family, at that moment we are the only ones actively doing the dying. Not only can no one intervene and die on our behalf, but to the extent that they have not yet died themselves, they cannot fully understand what it is to be dying. Just as our individual death cannot be understood by even our most beloved outsiders, neither can our own notions of a dignified death be decided for us by society writ large. If I am the only one doing my dying, should I not then be the only one deciding at which point my dying is no longer dignified?

It is with a resounding “no” that opponents of the movement answer this question. For them, dignity is both inherent and resists subjectification. Dignity comes from the very nature of human life and through living in a human way. The only thing powerful enough to strip your inherent dignity is the failure of outsiders to recognize you as dignified human. Dignity, then, is both universal and relational. In this way, they believe that dignity must be protected and guarded. Rather than ascribing dignity to personal and internal deliberations as advocates of the right to die maintain, those in opposition draw upon an understanding of dignity that is externally deliberated and can only be stripped by another’s refusal to recognize human dignity past the disability. This could be seen as an implementation of “anonymous care” – a way in which “one cares, but

indifferently” (Stevenson 2014, 7). Simply allowing another the dignity which all humans maintain requires little effort to build a relationship of interaction with that person. All that is necessary is the recognition of them a part of the human species – hands off and bereft of individuality.

While an abundance of literature exists on the right to die movement, very little comes from an anthropological perspective. Frances Norwood’s (2009) recent exploration of “euthanasia talk” in The Netherlands provides one notable exception to this glaring absence. Throughout *Maintenance of Life*, Norwood takes on the term “euthanasia talk” as a way of understanding how the Dutch practice of euthanasia is “predominately a discussion that only rarely culminates in a euthanasia death” (ibid., 18). She writes that simply talking about the possibility of an assisted death “serves a palliative function, prolonging life and staving off social death by providing participants with a venue for processing meaning, giving voice to suffering, and reaffirming social bonds and self-identity at the end of Dutch life” (21). By talking in a very real way about death’s imminence, the men and women exploring euthanasia as an option maintain a sense of pertinence in lives of those around them as well as their own. It is the intention of this thesis to add to Norwood’s observation that more than simply remaining pertinent to the lives around them, advocates seek to continue creating themselves until the actual end-of-life.

Anthropology of Death and Dying

The lack of anthropological inquiry on the physician assisted death hardly reflects the discipline’s interest in death and dying. As the structural anthropologist Claude Levi-Strauss once suggested, anthropology may be “*nothing but* the study of death” (Fabian 1972, 560). Classical anthropologists often encountered death and dying while studying the origins of religion, myth or ritual among what they considered to be “primitive” and “savage” societies (Young and Rees 2011;

Kaufman 2004). James Frazer, a prominent social evolutionary theorist, attempted to discover the origins of man's conception of God by examining "primitive" and "savage" responses to death. As that problem which "has very naturally exercised the minds of men in all ages" (Frazer 1913, 32), Frazer utilized the rituals and understandings of death by "primitive" peoples to mark out various coordinates along the evolutionary progression of religious belief (see also E.B. Tylor 1871). French sociologist, Robert Hertz's (2004), foundational text on funerary rituals explored the relationships between death, corpse, soul and mourners. Through this study, Hertz emphasized that "death does not coincide with the destruction of an individual's life; death is a social event and the beginning of a ceremonial process by which the dead person becomes an ancestor; and finally, death is an initiation into an afterlife, a rebirth" (Kaufman 2004, 245; see also Davies 2000; Palgi and Abramovitch 1984). While the father of modern anthropology Bronislaw Malinowski similarly studied burial rituals, his functionalist approach focused much more on the ways in which death effects social cohesion. For Malinowski, death breaks the "normal course of life and shakes the moral foundations to the core" (1948, 34) and "threatens the very cohesion and solidarity of the group" (ibid., 35). Malinowski writes, "[...] in the duties of a series of commemorative or sacrificial ceremonies - in all this religion counteracts the centrifugal forces of fear, dismay, demoralization, and provides the most powerful means of reintegration of the group's shaken solidarity and of the reestablishment of its morale" (ibid.). Or, in other words, the ritual surrounding a community member's death, re-establishes the bonds within the community and allows them to move forward.

Though these texts proved to be influential pieces of classical anthropology, with the growth of reflexive and interpretive anthropology toward the end of the 20th century glaring absences were noted. In a comprehensive review of the anthropological literature on death up to

the mid 1980s, Palgi and Abramovitch note that “when reading through the anthropological literature in one large sweep, one is left with the impression of coolness and remoteness. The focus is on the bereaved and on the corpse but never on the dying” (1984, 385). This highlights the othering tactics that had become a greater concern for anthropology in general. Twelve years earlier, Johannes Fabian’s scathing critique (1972) of the “parochialization,” “folklorization” and “othering” tactics prevalent throughout previous anthropological accounts of death attempted to create a space for talking about the deeper emotional and social realities of death and dying – both “ours” and “theirs”. For Fabian, “progress in understanding will depend on our ability to free the notion of death from its encapsulation in behaviour, custom and folklore and to restore the experience of the termination of individual life to its full problematic status” (ibid., 554). Death and dying effect everyone, everywhere – even the anthropologist. Fabian was interested in having the anthropologist integrate this reality within the scope of their work. Later, paraphrasing Geertz, Fabian writes that a cultural reaction to death “is sociologically interesting not because ... it describes the social order (which, insofar as it does, it does not only very obliquely but very incompletely), but because ... it shapes it” (561-562). The movement from classical anthropologists’ conception of death as simple rip in the fabric of society in need of mending is clear. While remaining a rip, death and dying simultaneously enter the space of constitutive element of that very same fabric.

Complementing Fabian’s critique, the anthropologist Renato Rosaldo similarly criticized anthropologists for treating death “as if they were positioned as uninvolved spectators who have no lived experience that could provide knowledge about the cultural force of emotions” (1984, 193). Indicative of the larger reflexive turn in anthropological praxis, Rosaldo’s reproach calls on anthropologists to remember their place as “positioned subject” connected to and influenced by

their own experiences with death and dying. Ruth Behar's *Death and Memory: From Santa Maria del Monte to Miami Beach* (1991) serves as a powerful exemplar to the use of reflexivity in accounts of death and dying. As Behar effortlessly weaves her way through the reflections, memories and stories offered primarily by elderly members of a rural Spanish village, movement of the place/space/ritual of death and dying gradually becomes visible. Moments of disagreement between elderly and young demarcate shifts in conceptions of responsibility and proper responses of bereavement. Goosebumps invade as she recounts the immeasurable distance between one woman's experience of washing her dead mother's body and her granddaughter's outward signs of horror at the thought of such a tactile encounter with death. Quick to place such encounters with death in the "distant rural past," the granddaughter's "denial of coevalness with her grandparents seems too brusque" to Behar. Yet as she sits there listening she tells us her own grandfather is home in Miami dying and "I realize I am not there with him. I have chosen the enormous distance, to hear how others die because I have not resolved how to be there with him" (ibid., 354). As Behar folds her own experiences and thoughts of her grandfather's dying a dual sense of loss – that of human loss and that of loss of tradition – evinces itself and rises to the surface while reaching out to latch itself to the reader. She claims that wrapped within her ethnographic work, is her "effort to remember" (375) – to remember her dead grandfather, to remember death as it used to be for these Spanish villagers, to remember her own Jewish heritage. Everything all wrapped into one rather untidy package. Whereas death has often left anthropologists on the "brink of silence and speech" (377), Behar's reflexive mingling of her own story works as an "ice pick [chipping away] at the conventional forms of representing and narrating the interplay between death and anthropologist" (378).

Behar's self-reflexive method (see also Panourgia 1995; Rosaldo 1984) partially informs this thesis. The loss of my own mother as a teenager has been a prominent feature in the way I understand this work. While initially hesitant to be a part of my supervisor's greater project on the right to die, my mother's dying continually worked its way to the fore as I asked my interlocutors to express themselves. What experiences had they had before?

Of course this is not the only direction in which the anthropology of death moved. The movement away from classical anthropology's evolutionary exoticism that looked to "supposedly premodern cultures for solutions to a modern conundrum" (Langlitz 2012, 19) included the development of an "anthropology at home" (Peirano 1998). Whereas anthropologist working reflexively through death and dying typically sought out Others with which to work, anthropologists interested in working at home focused on their native locales. That being said, until quite recently, anthropologists continued to ignore modern medicines' role in our dying and assumed it "to have evolved beyond the superstition, religion, and value laden beliefs so clear to them in traditional medicine" (Lock 1988, 3). As Ariès (1981) has noted, for most of written history death was far from the purview of the physician. However, by the end of the 18th century death had begun to be realized as locatable within the body (Kaufman 2004) and well within the realm of the physician. Moving beyond this, sociologists Glaser and Strauss (1965, 1968) explored the way in which the modern American hospital shaped dying and gave it a specific trajectory.

Since Glaser and Strauss' seminal work in the area, several anthropologists have taken on the ways in which pervasive in(ter)vention of various biomedical technologies at the end of life has increasingly complicated the process of dying (see Lock 2002 for one example). Less often, anthropologists hone in on the various systems contributing to a variety of ways in which death is structured and ultimately facilitated and allowed to happen. In one such exploration, anthropologist

Sharon Kaufman traces out the ways in which “the decision-making required by medicine and the [American] hospital system” have brought “death into life” and created what she calls “a zone of indistinction between *life* and *death*” (2005, 83). Sustained by paradox, this “zone of indistinction” – which “demands that everyone in the system deliberate the value of *life itself* in its most vulnerable forms” (ibid., 318) – partially derives from the pressure that time places on patients, families and hospital staff alike to make decisions on what to do next. Bureaucratic and institutional mandates focused on “moving things along” often clash with biomedical technology’s capacity and the physician’s desire to “give every patient the most appropriate care possible” (96). Nonetheless, Kaufman notes that “doctors and other hospital staff learn to see treatment and care in terms of *where patients are going in the* [greater healthcare] *system* as well as in terms of payment schemes, institutional regulations, and treatment logics” (97). Out of the merger of these factors, decisions are made on which treatment pathways patients ought to be directed toward.

This leads us to one final example of how anthropology engages death. In “Negotiating the ‘Good Death’: Japanese Ambivalence about New Ways to Die” (2001) Susan Orpett Long explores both how a “good death” has traditionally been understood in Japan and how with increased options for how to die have been received ambivalently even though they may be pursuing the same “good death” that has been traditionally sought. Traditionally she found that a good death (and these may not be specifically Japanese) meant one that is: free of pain in its final stages, surrounded by family, personalized so that it fits with the way one has lived and free from burdening surviving family members (ibid., 273). The new ways of dying discussed in this article, such as euthanasia and hospice, are received with ambivalence on two levels - personal and interpersonal - due to contradictions and mixed messages. Personal ambivalence, Long argues, was found in the contradictions between the traditional value of not being a burden on one’s family

and the desire to be cared for through hospice. And interpersonally in the broken communication between caregivers and individuals in which the caregivers could balance and demonstrate how new ways to die align with traditional values. For Long, increased ambivalence should be seen as “the reasonable response to the expansion of the range of meanings of dying and the increased complexity of negotiating them in the context of change” (285).

Frameworks: Conceptualizing the Field

As was noted earlier, the literature on assisted dying is often approached through juridico-ethical or biomedical discourses, where one’s desire to access the assisted death can either be understood clinically or rationally. Their desire (even simple interest) is thus confined to the strictures of biological, psychological and ethical norms (i.e. “This is (un)allowable because...” it is (un)ethical, and/or he is (in)competent, psychologically (un)stable, in (ir)remediable pain, etc.; or “This patient wants this because ...”). And though these insights are indeed valuable, they often fail to account for the situatedness of ethical thought and transience of desire as well as tending to take for granted the biomedical perspective that “‘wellness’ – the avoidance of disease and illness – has become a ‘virtue,’ for some, a secular path to salvation” (Lock and Nguyen 2010, 28). Thus, rather than attempting to pin down *what* the motivators behind the desire are, this ethnographic research relied on the subjective positioning of individuals, and conceptual framework of subjectivity, to learn more *how* the assisted death could lead to a more meaningful dying.

The variety of theoretical and conceptual understandings across disciplines, makes it difficult to understand and often tends to complicate the concept more than clarify. Anthropology too, has had problems with settling on a single understanding. For instance, Tanya Luhrmann has written that anthropologists’ use subjectivity “to refer to the shared inner life of the subject, to the

way subjects feel, respond and experience” (2006, 345). But this seems a rather toothless analytic as it does not address questions related to what ends are people feeling, responding and experiencing? In another understanding, the anthropologist Sherry Ortner (2005) understands subjectivity as the “basis of agency,” the primary mover and decider in how we intersubjectively act both upon and within the world. And though it is through this subjectivity that we both make and seek meaning, its development remains forever subsumed within cultural constraints of acceptable behaviors - “perception, affect, thought, desire, fear” (2005, 34) - that unconsciously affix themselves to our being.

There are at least two aspects of the conceptualization that are problematic today. One stems primarily from the use of one contested concept to define another contested concept. If our subjectivity forms the basis of our agency, then what is agency (Emirbayer and Mische 1998)? The second problematic aspect of Ortner’s understanding arises in how she situates subjectivity rather closely to a Geertzian understanding of culture as “public systems of symbols and meanings, texts and practices, that both represent a world and shape subjects in ways that fit the world as represented” (Ortner 2005, 37). But how are we to distinguish cultural boundaries in our globalized world? Or, as Michael J. Fischer writes “culture is not a variable; culture is relational, it is elsewhere, it is in passage, it is where meaning is woven and renewed often through gaps and silences, and forces beyond the conscious control of individuals, and yet the space where individual and institutional social responsibility and ethical struggle take place” (2003, 7). In other words, culture is not a variable from place to place or person to person, but something that could be identified as continuously negotiable. If we are supposed to draw our subjectivities from a slew of cultural backgrounds, where are these backgrounds? Following this path would have felt forced

as many of the people I worked with recalled stories and examples from diverse backgrounds and could hardly be seen as being written by a unified Canadian cultural text.

Rather, the philosopher Michel Foucault's articulation of the "care of the self" seemed to allow people more openness and for this reason has helped to frame this thesis. Foucault writes that the relationship which one ought to have with oneself can be called ethics and "determines how the individual is supposed to constitute himself as a moral subject of his own actions" (Foucault 2010, 352). Subjectivity understood from this perspective says neither that we are by-products of our thoughts, nor are we subsumed within cultural texts that write us out unconsciously. Rather, for Foucault, subjectivities inform minor resistances against such individuating practices. This relationship with oneself has four primary aspects: ethical substance, mode of subjection, techniques of the self, and teleological end goal. For the purposes of this thesis, the third aspect, "techniques of the self" will be focused on.

Foucault's third aspect of the care of the self is "what are the means by which we can change ourselves?" (ibid.). This becomes what he calls the techniques of the self. So if we have in the previous two aspects, that which is to be judged, the way in which this will be judged, here is a sort of government of the self – how to change ourselves or orient ourselves toward that which is the end goal. If we are to be living as if we are dying as a way of achieving a life well lived, what are the ways in which we attain this? And this is something that will be worked out further in chapter's two and three. In chapter 2, I will work through the ways in which advocates within the movement desire to care for themselves as a spiritual practice. In part, assisted dying is much less about whether or not the death actually occurs and more about transforming oneself as capable of accessing the good death. Of course there are people who will be much more interested in the death

actually happening, many of the individuals that I spent time with were much more concerned with, in a sense, their “soul” toward the end of life.

There are a couple of other quotes that seem important from Foucault. “What strikes me is the fact that in our society, art has become something which is related only to objects and not to individuals, or to life. That art is something which is specialized or which is done by experts who are artists. But couldn’t everyone’s life become a work of art? Why should the lamp or the house be an art object, but not our life?” (350). This is something that I am trying to get at with how my individuals work through the end of life. There is some sort of aspect of creation that they are looking out toward. They are trying to create themselves – creating works of art.

Nonetheless, as mentioned previously, Foucault tends to focus on subjectivities as minor resistances to established norms which can, at times, feel constrained. For this reason, I have also followed Biehl, Good and Kleinman who make subjectivity a much more palatable conceptual tool when by exploring the terminology itself as contingent and open (2007, 17). By embracing the uncertainty and contingency of subjectivity as conceptual tool, they embrace the realization that perhaps it cannot be pinned down just as “subjects are themselves unfinished and unfinishable” (ibid., 15). Thus, understood this way, subjectivity is subsumed under the project as a whole “to explore what matters most in people’s lives in the making and unmaking of meaning. Values and emotions are closely connected and are embodied and projected into domestic spaces, public life, and interpersonal struggles. We look through subjectivity to theorize not an intangible Subject but human conditions, to make sense of our ethical reflections on them, and to challenge anthropological work” (ibid.).

Methodology: Approaching the Unapproachable

As was mentioned earlier, throughout the 1970s and 80s, the historian Philippe Ariès (1981) repeatedly articulated his position that modern death had become “shameful and forbidden” to see. As we have already seen, there is a plethora of literature associated with death and dying, but how is it possible to talk about something that has become so taboo and personal? The goal of this ethnographic research was to explore how assisted dying could be seen as creating the space for a more meaningful death than readily available today. Of course, echoing Gandsman and Burnier’s (2014) question of whether or not we have to die with dignity, it could be asked whether or not we have to die in meaningful ways. And though the answer to this question is up to every individual, the reason I have chosen to explore assisted dying from this standpoint stems from my own personal experience with death and interest in how others make death meaningful. As was already written in the prologue, this experience has lingered and continues to pull at my thoughts.

The issue of assisted dying, otherwise known as the “right to die” social movement, attracts a variety of supporters with varied backgrounds and desired outcomes here in Canada. That being said, public discourse around the issue is often whittled down to what Wanda Morris, the former CEO of Dying with Dignity, calls “one elemental question: let’s be compassionate, isn’t it up to the individual to choose when and how to die?”. And of course, this is the primary marker of the issue. However, framing assisted dying purely in this way silences, or at least puts dampers, on the many voices in the movement. Though Wanda and other leaders of the movement both recognize and appreciate its diversity, to successfully reach their goal, a scatter plot with a path coursing through the highest density of “dots” must be followed. With this in mind, the several meetings, presentations or training sessions I attended (all through Dying with Dignity) were focused around one of two camps: what can be done to influence others into supporting our cause or how can we

currently implement our choice in death? Those in attendance interested in spreading the message of the movement were often invited to share their own stories (like my own in the prologue) with the group and receive feedback on how to do so more “powerfully.” But what could be more powerful than how one moves through a story themselves? And I am not saying that there is anything wrong with this, but it did seem to cut the organic nature of stories – the unfinishedness of stories.

I write the above to explicate two methodological points. The first is that by undergoing classic ethnographic participant observation, I was able to garner a greater understanding of the public structure of the movement. What are the messages being pushed by leaders and subsequently shared by individual members? How are these individuals interested in assisted dying trained to talk about the issue? Having more familiarity with these questions allowed for stronger navigation within the second methodological point. Over the course of my fieldwork I interviewed 24 individuals. And rather than following the course of training sessions where they were taught to amend and fit their story within some defined narrative structure, I allowed them to freely move between ideas, thoughts and feelings. Though I approached each interview with a series of questions I was interested in asking, I attempted not to force them but rather work them out organically.

Nonetheless, death and dying can still be incredibly difficult to talk about – especially with a stranger. This can be further exacerbated if you feel as though a researcher is simply using you for quotes and treating you as an object of study. For this reason, one of the most valuable aspects of my methodology, and I hate even putting this within the methodology section as it makes me sound trite, was opening myself to the people I spoke with. As such, barriers were often broken (at

least they felt as such) by my sharing my own story. And though this is in no means a purely reflexive thesis, I am impossibly wrapped within the pages that follow.

In addition to these interviews and the training sessions and meetings attended through Dying with Dignity, I was also present for one town hall meeting in Toronto and a panel on “palliative care and end-of-life decisions” at an Anglican church in Brockville, Ontario. At both of these events there were a variety of concerns expressed with upcoming legislation on assisted dying. That being said, by attending I was able to come closer to the opposition of the movement. As this thesis is largely situated around proponents of assisted dying and their experiences, thoughts and ideas on the meaningful death, it did help me to hear vocalized concerns of actual individuals rather than simply reading them in the newspaper or online.

Chapter 1 – This Ruling Changes Everything

6 February 2015. Once again, the overnight clouds had covered Ottawa with a thin dusting of fresh, powdery snow. Still overcast when I woke up, it was an extremely cold morning – somewhere around thirty below with the wind chill. Though I had intended on making my way to the Supreme Court to be present for their decision on the prominent right to die, *Carter v. Canada* case, the weather convinced me to stay in and watch CBC's live coverage instead. The decision promised to tell Canadians whether or not the criminal code's blanket prohibitions against assisting another person to die would be upheld or struck down as unconstitutional. But who goes to decisions anyway? CBC's cuts to the scene at the courthouse were encouraging as there were few people in attendance aside from the media and the lawyers/plaintiffs already hidden from sight.

This seemed an enormous difference from the overflow seating at the actual hearing back in October 2014. In October, I had shown up over an hour before deliberations were to begin and found myself at the back of a rather long line of individuals eagerly chatting about the case and waiting to be seated in the tiny courtroom. Though the courtroom ran out of space just before my spot in line, I was eventually let in twenty minutes before the end of deliberations. However, for the most part, I sat in the overflow seating arranged in the foyer. Myself and about fifty others, seemingly all law students, watched proceedings through a monitor displaying live feed of the courtroom and listened through one of those audio devices you rent at museums when you want more than the ten word descriptions below the exhibit. It was all rather blasé. The emotion with which the arguments were presented within the courtroom, though visible and audible, seemed to be lost somewhere in transmission. Thoughts and feelings escaped me as I sat staring at the monitor surrounded by seemingly limitless space. My overflow companions ceased to exist as all that could

be heard through the headphones tightly pressed against my ears were the voices correlating to the pictures on the screen and, occasionally, the disruptive fuzz of white noise.

The public debate over whether Canadian's held the legal right to an assisted death began in 1992 with Sue Rodriguez's, a 42-year-old mother living with amyotrophic lateral sclerosis (ALS), famous questions "If I cannot give consent to my own death, whose body is this? Who owns my life?" As her relationship with ALS developed, gradually tearing apart the already tenuous connections between her nervous system and the muscles supposedly beneath its control, Sue knew that her reliance on biomedical technologies to alleviate symptoms and sustain physiological life could only increase. Somewhere along this prognosticated line of decline, her dignity would have been forcibly removed and at this time she would like to be helped to die. However, the Canadian Criminal Code's blanket prohibition against aiding or abetting another person to kill themselves prevented physicians from engaging in this desire with Sue. In her mind, this was unacceptable and directly infringed upon her "right to life, liberty and security of the person" guaranteed in the Canadian Charter of Rights and Freedoms. Following a widely covered hearing, in October 1993 the Supreme Court passed down a majority decision in its first right to die case, *Rodriguez v. British Columbia*, denying the appellant her request to die with the assistance of a qualified physician.

Though the years following the Rodriguez decision had been anything but silent regarding assisted death, the issue lingered on the periphery of national attention until re-entering the limelight in 2011 with the opening of the *Carter v Canada* case in the Supreme Court of British Columbia. In January 2010 Kay Carter had travelled to the Dignitas clinic in Switzerland where physicians assisted her to end her own life. At 89-years-old Kay had decided that her life with severe spinal stenosis had become so warped that she no longer considered it as being lived or

livable. Death became the better option. On January 15, 2010, accompanied by her daughter, Lee, and a few other family members, Kay died in another country, within the confines of the home-y/clinic-y hybrid of Dignitas. Though her mother had finally accessed an assisted death, Lee realized that the immense amounts of psychological, emotional and financial strain required to obtain such a death hardly satisfied the desire for a “good death.” A short time after their return, Lee and her husband, Hollis Johnson, decided that this form of hidden and distant death was no longer acceptable in Canada and began the process of filing a court case with the help of the British Columbia Civil Liberties Association (BCCLA) and a number of fellow plaintiffs.

So there I sat, alone and waiting, in the dark of my basement with only the television’s glow and the authoritative voices of talking heads keeping me company. It was nearly 10am before Grace Pastine, litigation director for the BCCLA, appeared on screen walking toward the mess of journalists jostling for better positions around the small podium. The case had been won. Pastine proclaimed “this is a tremendous victory for human rights and compassion at the end of life. What this decision means is that Canadians who are suffering unbearably at the end of life, will have a choice now.” As I continued watching Pastine speak, my mind began drifting to the individuals I had already encountered through my research. Lost in my own cloud of thought, the camera flit about incessantly gathering perspectives and individuals to parade before the masses. Words like “momentous victory,” “change,” “recognition of rights,” “dignity” and “dignified” bounced guilelessly off my tympanic membrane. I remember wondering how this decision would actually enter into relationship with and become enmeshed in the lives of my informants. Then the cloud burst and I was unwillingly rained back down onto the drama unfolding at the Supreme Court.

Opponents of the movement lamented the Court’s ruling and promised to continue standing up for the “vulnerable,” “disabled” and “elderly” that would be disproportionately affected by this

decision. Again, the talking heads rehashed old and new arguments involved in the history from Rodriguez to now. Ultimately, however, the lens focused on the powerful sentiments of victory and change that this ruling had summoned. With all eyes on him, Steven Fletcher, a quadriplegic member of parliament who had tabled several bills in attempt to implement new legislation on assisted death, exclaimed that this is an:

Existential, moral issue that affects everyone who is alive today and everyone who will live in Canada in the future. [This] ruling today by the Supreme Court is the most important ruling since the 1982 Constitution. It speaks to so many fundamental values and what we as Canadians believe and expect of each other ... to be merciful, compassionate, empathetic and understanding and respect people to make the best decisions for themselves. And up until 20 min ago, Canadians were not allowed to make the best decisions for themselves because they were prohibited from having this choice.

Beaming, Lee Carter, the primary appellant's daughter, read her prepared statement: "Kay would smile at this outcome and the conversation it has initiated about death and end of life options. Justice, dignity and compassion were defining qualities of my mother. This ruling now extends those same elements to individuals seeking a humane and dignified death in this country. A huge victory for Canadians and a legacy for Kay."

For advocates of the right to die movement, the tides of change were growing. Their calls for the acknowledgement of their right to access to the "good" and "dignified" death via assistance had finally been heard and were now on the path to being solidified. Aside from the near daily affirmation from various editorials, blogposts and interviews, within a month of the decision, the BCCLA released a documentary entitled "This Ruling Changes Everything: The Story of Carter v. Canada" (2015) detailing thoughts and actions of the plaintiffs and lawyers throughout the process. Of course, opponents' voices have not disappeared and actual legislation has yet to be written, but a certain air of victory reigns – the Supreme Court ruling changed everything.

Life, Death and Medicalization

Perhaps Pastine, Fletcher and Carter correctly assume that this ruling changes everything, but the “everything” that has changed remains unclear. What exactly are the changes these individuals have directed our attention toward? One obvious aspect of change certainly involves the legal status of assisted dying in Canada. Regardless of the actual legislation and further safeguards created through Parliament by June 2016, the desire of a competent adult under intolerable suffering due to a “grievous and irremediable” medical condition to have a physician assisted death will no longer put them (or their assistant) in contention with Canadian law. But if we are to take the BCCLA’s (somewhat self-aggrandizing) statement literally, legality and choice cannot be the only realm of change. Thus, this chapter will trace out the way in which the statement that “everything” has changed might be understood outside of recent legalization. What are the medical as well as sociopolitical ways in which this decision has changed everything? Furthermore, in order to address my research question of how the assisted death could be seen as creating the space for a more meaningful way to die, this chapter will tease out some of the ways in which it came to be seen as a necessary change.

What follows, then, is the briefest possible reflection on the contemporary problem of death. If Lisa Stevenson’s goal throughout her book on suicide among Inuit youth was to describe the way in which “our desire to ‘make live’ at the level of a population can sometimes be experienced as murderous” (2014, 18), then this chapter’s is to examine how our desire to “make live” could come to be seen as an offense to human dignity in need of correction. To do this, we will work our way through the growth in medicalization of the human body and the advent of the artificial respirator. This well known life extension technology has been chosen due to its near ubiquitous presence at the end of life for individuals experiencing illnesses that fall within the Supreme

Court's specifications of "grievous and irremediable medical conditions causing enduring suffering" (i.e. Amyotrophic Lateral Sclerosis and Parkinson's) when requesting a physician assisted death. Several advocates of assisted dying have also publicly expressed their desire to die before being "hooked up and kept alive" (Laforest 2011) by various medical devices like the respirator. From there, we will look into the role the respirator has played in problematizing death and dying. Whereas death had once been understood as the cessation of respiration and cardiopulmonary functioning, the respirator allows a body to continue "living" well past this point. By exploring the court case of Karen Quinlan, a young woman kept alive by artificial respiration, we can begin to see the contours of an emergent contestability of death. While death's, like those of Quinlan, technically qualify as passive hastening of death since they are the withdrawal of treatment rather than the active hastening of death sought in assisted dying, it sheds light on the way in which death often requires a decision and can no longer be considered as merely "natural" occurrence. That death requires a decision beckons the question of who decides when death is more valuable than life. By briefly looking at the decriminalization of suicide in Canada we can begin to see the way in which the individual began to be seen as the primary decision maker rather than the state or medical field. Though suicide continues to be described as a public health epidemic, Canadians, whether terminally ill or not, now had the "right" to take their own life. In essence, this chapter traces out one way in which when and/or how one dies can be understood as having become a necessary choice. If everything has indeed changed, perhaps the everything indicates the emergent necessity of choice at the end-of-life since the early 20th Century.

* * * * *

In *The Birth of the Clinic*, a book about “about space, about language, and about death; about the act of seeing” (Foucault 2003, ix), Foucault traced out the emergence of the modern physician’s “loquacious gaze” which made “the *clinical experience* possible ... [so] one could at last hold a scientifically structured discourse about an individual” (ibid. xiv). Placed within the perceptive lineage of Cartesian rationality, modern medicine created a physical space where, “the *object* of discourse may equally well be a *subject*, without the figures of objectivity being in any way altered” (ibid). Rather than simply changing the language of classical medicine, this 19th century emergence occasioned a change of “syntactic form” (Dreyfus and Rabinow 1983, 15) – “The figures of pain are not conjured away by means of a body of neutralized knowledge; they have been redistributed in the space in which bodies and eyes meet. What has changed is the salient configuration in which language finds support” (Foucault 2003, xi). Within a few years of Foucault’s publication, Irving Zola argued that medicine was becoming a major “institution of social control” and “new repository of truth” which made “absolute” and “final” judgments on individual’s lives in the “name of health” (Zola 1972). Of course, this neither happened overnight nor presents itself as inherently terrible, but that was beside the point for Zola. What he sought to excoriate was the unwittingly (perhaps apathetically?) naïve acceptance of the “medicalizing” of daily life – the making of “medicine and the labels ‘healthy’ and ‘ill’ *relevant* to an ever increasing part of human existence” (ibid., 487).

Like some *mise en abyme*, modern medicine approaches the variety of bodily processes by parsing them out into stages of orderly and observable characteristics. Perhaps infinitely discoverable, “medicine offers modern man the obstinate, yet reassuring face of his finitude; in it, death is endlessly repeated, but it is also exorcized; and although it ceaselessly reminds man of the limit that he bears within him, it also speaks to him of that technical world that is the armed,

positive, full form of his finitude" (Foucault 2003, 198). Though death approaches nonetheless, the human body should be perceived as an intricate machine, an object, lying in wait for tune-ups or replacement parts. "I consider the body of a man as being a sort of machine so built up and composed of nerves, muscles, veins, blood and skin, that though there were no mind in it at all, it would not cease to have the same motions as at present" (Descartes 1993, 97). In this way, death, as the result of the breakdown of parts, could not forgo medicine's irresistible urge to objectify and make known. Knowing death intimates mastering death. Mastered death is eternal life.

In addition to Zola and Foucault, several other academics similarly traced out the ways in which human biology was continually becoming object of study passively waiting to become known through the medical gaze. Joining himself to Zola and the numerous other's reflections on medicalization of life, Philip Ariès set out to explore the ways in which death has been understood and experienced across much of Europe and North America. Whereas the dying bedside would have formerly been the space for loved ones (Ariès 1981; Lavi, 2007), the Cartesian underpinnings of modern medicine's objectification of the human body has taken on death and dying as technical problems "managed within the confines of the hospital by medical experts and enveloped in a professional cloak of unpredictability and medical mystery" (Seymour 1999, 692; see also Conrad 1992). Rather than encourage recognition of the inevitability of death, increased medicalization has taught us to fear, fight and prevent death at all costs. Theoretically, we understand that death will occur at some point, but somehow we are still surprised when it does. Death waits at the bottom of the escalator we spend our days fighting in a losing battle as we run against the tread. This can be understood through the various messages promoting healthy foods, daily exercise and the healing power of the right medicinal cocktail – failure to comply is interpreted as failure to take care of the self (Illich 2003).

Death no longer seems to offer insight into life, but rather forces doleful acceptance of personal and medical failure and “jars the routine of daily life” (Ariès 1974b, 7). The ability to attach oneself to bleeping, dripping, life prolonging machines seems to have tricked us into the notion that death bears little burden on our lives. In Ontario today, average male life expectancy is 79 years of age and 84 for females – that’s up more than thirty percent from 59 and 61 respectively in 1920 (Statistics Canada 2012). Life expectancy has increasingly become utilized as a tool for measuring success within national development. The greater the life expectancy, the *better* the nation. From this approach, when confronted with end of life situations, we Westerners find ourselves confounded by the question of whether life should continue to be fought for at all costs or if death’s inevitable companionship should be graciously embraced.

The 20th century has witnessed the rapid growth of death-delaying/life-sustaining medical technology and technique. Development and normalization of antibiotics – beginning with mass production of their prototype, penicillin, during WWII (Bud 2007) – dramatically reduced deaths resulting from illnesses such as tuberculosis or infections from surgery or wounds. As Lewis Thomas writes, “bacteria could be killed off without at the same time killing the patient” (1992, 65). As an example of a biomedical technology, the dialysis machine, created by a Dutch physician in the early 1940s, took on the responsibility of the ailing kidney filtering impurities from the blood. Though the original prototype could only treat those with temporary kidney failure due to the poor durability of human blood vessels when hooked to the machine, by the 1960s artificial, Teflon veins in the form of a permanently implanted cannula and shunt allowed the machine/body

connection to be made repeatedly and indefinitely on the chronic patient (Rothman 1997). These two technological modes of intervention on the (f)ailing body represent only two among limitless possible other pathways. And while this particular thesis' focus is not life-extending medical technologies, they have become integral aspects of "normal" end-of-life here in Canada and much of the West. So normalized and powerful that they continually "draw us into a defined space with a riveting intensity, shutting out surrounding realities to enhance the importance of the action or place to which they take us" (Reiser 2009, 187-188). Medical technologies focus on "broken" parts within our bodies and endeavor to recreate the functionality of these parts.

As one such technology often present in the deaths described as horrific by assisted dying advocates – the artificial respirator (or ventilator) – will be briefly explored. The ventilator hones in on respiratory failure all the while forgetting the human behind the lungs. Once within their "biotechnical embrace" (Good 2001), medical technologies create spaces of forgetfulness. These life sustaining technologies address our lives all the while forgetting our various relations with death. Reiser argues that "the subject of care is the person who cannot be understood fully if divided into parts by the thinking and technology of medicine" (2009 188).

In the early 1900s the poliomyelitis virus spread with epidemic proportions in North America and Western Europe. Among the wide array of symptoms associated with polio, the near total paralysis of the diaphragm's muscles removed the individual's ability to breathe autonomously (Rothman 1997) and often resulted in death. Something was needed to sustain the "breathing of polio victims long enough to give their bodies time to recover and take over the task" (Reiser 2009, 54). In the late 1920s Philip Drinker and his colleague, Louis Shaw, responded to this challenge by inventing the iron lung, a massive cylindrical chamber large enough for a human body, head excluded, that created a negative pressure seal and resulted in a more regulated

breathing. For many, this was enough to stave off an imminent death; however, it was not until 1952 when a voracious polio outbreak in Copenhagen swung wide the doors of development for a more efficient ventilator. Overwhelmed by the mass influx of patients in need of respiratory aid, the physicians in charge of polio cases at Copenhagen's Blegdam hospital turned to the resident anesthetists who had been experimenting with another form of artificial respiration (intermittent positive pressure ventilation or IPPV) that forced air from a manually operated bag into the lungs through a slit in the windpipe. Though IPPV needed manual manipulation and multiple well trained internists to deliver the artificial breath, survival rates doubled throughout the outbreak (ibid., 58). Soon after, the iron lung was abandoned and greater effort was put into the development of IPPV and what has grown into becoming today's ventilator.

Though the full story of the ventilator would require one to "meander through a veritable Latourian network of entanglements" (Lock 2000, 239), its rise to prominent figure at the end of life was set. However, the ventilator's increasing utilization as biomedical intervention did not come without some discomfort and reservation. Its rapid ascension and unthinking application to the nearly dead bodies created various spaces of uncertainty. Whereas many of the individuals hooked up to these machines would most certainly have died within hours or days, once biotechnical hybridization occurred the ventilator's efficiency at preserving life long past what previously thought possible was both incredible and, at times, disconcerting. Various relations of uncertainty – whether the physician's desire to acknowledge the appropriate timing of death and at which point the organ harvest could begin (Lock 2002), or in the relative's concern for the remaining person-ness of this person – pushed death's emerging contestability to the fore. When does death occur? At what point is the artificially breathing body-individual nothing more than a body?

At a loss, several physicians reached out to traditional gatekeepers of knowledge about life and death. One prominent gatekeeper, the Catholic Church, was consulted through Pope Pius XII who, in 1957, responded that “human life continues as long as vital functions – as distinguished from the simple life of organs – manifests itself” (Pope Pius XII). Though the Pope clarified that it was not the Church’s role to deliberate the exact moment of death, by articulating “God’s” position on what constitutes life – in turn separating “the biological from the religious and social self” (Reiser 2009, 63) – he seemed to condone the removal of artificial respiratory technology. And while the Pope’s interest in the contestable death provided some sort of moral support, debate within the medical community continued and in 1968 a committee composed of thirteen faculty members from Harvard University – which included a professor of theology, a lawyer, a biologist, a historian of science, and a group of physicians – convened to examine the status of irreversible coma as criterion for death. What resulted was a new conception of death centralized around the measurement of brain functionality – what has become known as “brain death.”

While death had previously occurred with cessation of cardio-pulmonary functioning, introduction and development of the ventilator contested and confused this traditional definition. Increased capability of solid organ transplantation mixed with increased uncertainty of death resulted in an utter imperative “to agree upon a diagnosis of death that could be clearly pinpointed in time, and as an event, rather than an indeterminate process” (Lock 1996, 580). The Harvard committee set about ordering a series of criteria that would allow physicians “to declare that the patient had a permanently non-functioning brain and therefore had died” (Reiser 1977, 48). Once these criteria had been observed, any artificial form of life-sustaining technology could be removed and the patient allowed to “naturally” expire.

The case of Karen Ann Quinlan crystalized concerns of problematic life-death resulting from life-sustaining technology and the committee's new formulation of brain death. In April 1975, 21-year-old Quinlan was rushed to the hospital having lost consciousness following a party with friends where breathing ceased for at least two 15 minute periods. Upon arrival, the medical staff immediately hooked her up to a respirator and initiated life-saving procedures. While she survived this initial balancing act between life and death, within days Quinlan's primary physician, a neurologist, considered her as within a state of irreversible coma, a persistent vegetative state (PVS), where cognitive capabilities had been lost, but autoregulation of blood pressure and swallowing remained. Though Quinlan was seemingly incapable of cognitive thought and relied on a ventilator to continue breathing, the Harvard committee's criteria for brain death had not been met – she was not dead. In light of this, the physicians refused to take Quinlan off of life support at the request of her family. After months of deliberation and following an initial refusal, the Supreme Court of New Jersey finally noted that Quinlan's father was her legal guardian and arbiter. With this power, he obtained the right to interpret her desires for life, death and medical treatment. If he could find a physician willing to label his daughter as “basically” dead, he could request her de-intubation and return her to the “natural” course of dying and death.

Within months of the court's decision, the Quinlan's removed their daughter from what was thought to be the only thing sustaining biological life. Karen lived another ten years, bedridden and unresponsive ... but that's beside the point. Whether she actually lived or died matter little. More importantly for Americans (though the Quinlan case was well documented in Canadian media, there were no direct consequences on the Canadian public), a precedent had been set – life and death could be contested from outside medicine. Remember, just a decade earlier, a small group of professionals had gathered at an American university to establish the universal truths of

modern life and death. Death, it had been decided, occurs at the cessation of full brain functionality². But what of the waiting period between brain death and life? That space of not-quite-yet-dead-death. The Quinlans, the court and their supporters grabbed hold of this space of liminality and contested the medical opinion. Medical uncertainty regarding this not-yet-dead-dead-body and the Quinlans' decision to remove the artificial respirator indicate that "life and death are not properly scientific concepts but rather political concepts, which as such acquire a political meaning precisely only through a decision" (Agamben 1998, 164). Decision as prerequisite for life. One must decide to live or die.

The publicity of ethical, moral, political, legal and medical debates (like the Quinlan case) surrounding these increasingly available life/death liminalities, intermixed with personal encounters of the other's extended and "bad" death in the hospital as well as fears of premature organ reaping, have partially contributed to a space from which physician authority could be challenged (Rothman 1991). Coinciding with the upsurge in a series of other movements (i.e. Patient Rights, Informed Consent, Civil Rights, Feminism, Gay and Lesbian), patient autonomy and individual choice over medical intervention slowly crept into a space of co-authority once inhabited solely by physicians or priests before them (Lavi 2007, 4). This is not to say that the physician's expertise has been removed altogether, but rather that it has become more of a guide, a repository for "knowledge" from which to draw diagnostic-prognostics, methodological and statistical information as well as expert *opinion* on desirable courses of action at the end of life (not to mention facilitation of chosen interventions). As experts, physicians remain situated at the gates of biomedical death knowledge, co-keepers of the "line" separating too much intervention from too little. However, as living beings unable to escape or rise above the plight of death that

² However, as Truog (1997) and Hershenov (2003) among others have pointed out, even the term brain death is incoherent and confused.

other living beings face (Canguilhem 2015, 188), neither physicians themselves nor the systems in which they operate have been “effective in recognizing [the line] or foreseeing the consequences of crossing it” (Kaufman 2015, 2).

If physicians are similarly at a loss for where exactly the line between life and death lie, who exactly is allowed to make this decision and when? While Karen Quinlan’s story qualifies as a passive hastening of death through the withdrawal of medical intervention, what sort of allowances should be made for someone interested in actively hastening death? As has already been noted in the first chapter, questions of this nature have extensive legal and ethical literature, so I’ll not delve into creating an argument here. Rather, what is important for this thesis is to mark out yet another precedent set around the 1970s. In 1972 the Canadian parliament decriminalized suicide. And though it has since remained within a “compulsory ontology of pathology” (Marsh, 2010, 31), this decriminalization suggests a recognition that the decision to kill oneself is one’s own choice. Defending the decision to remove attempted suicide from the Canadian Criminal Code, Minister of Justice Otto E. Lang argued that “this is not a matter which requires a legal remedy [as] it has its roots and its solutions in sciences outside of the law” (1972, 1699). Whether or not one has the right to choose suicide is not the issue. Of course, Lang continues to situate such desires as deviant, but this statement also allows for an understanding of suicide as personal choice. In a recent anthropological exploration of suicide, Munster and Broz write that the clinical conceptualization of suicide “presents it as a pathological and individual act, committed with willful intent, full consciousness and unambiguous authorship” (2015, 3). They say later that the World Health Organization has even replaced the terminology of suicide or attempted suicide with “intentional self-harm” which “clearly highlights the centrality of intentional agency” (ibid., 12).

In other words, while suicide remains a problem to be corrected, even the World Health Organization has recognized the rights of individual choice in such decisions.

Though advocates for assisted dying are clear that suicide and physician assisted dying are not one and the same, the precedent for accepting suicide as individual choice was called upon throughout *Carter v. Canada*. Again, as with the case of the artificial respirator and other biomedical technologies, the decriminalization of suicide has not in and of itself created a space from which assisted dying could become legalized. Instead, by briefly tracing out the way in which the artificial respirator and decriminalization of suicide in Canada have each played a part in complicating the notions of life, living, death and dying, I have attempted to make clear death's contemporary contestability. Whereas infections and organ failure had once meant certain death, with the help of biomedical technologies like penicillin, dialysis machines and the ventilator, death could be temporarily staved off. Now, rather than dying quickly, there is the option of becoming chronically dying or dying for a very long time. The ventilator's presence in this period of chronically dying has been so pervasive that death's very definition needed to be redefined. At this point medical mastery/expertise in matters of life and death no longer serves as the definitive truth on what is life or death. Rather, using the *Quinlan* case as "strategic exemplar," I attempted to show death as slowly creeping into the realm of necessary personal choice.

Perhaps this necessary choice is the "everything" that Pastine, Fletcher and Carter assumed to have changed. While I am not arguing that the ventilator or decriminalization of suicide are in themselves responsible for the emergent necessity, as they are often referenced by advocates for assisted dying I have attempted to trace their contributions. Though still confined within frameworks of bioethics and legality, death now relies much more on the individual's choice to invite it in. Advocates of an assisted death are acutely aware of this need to decide on life or death.

Barbara, a former social worker for individuals working through end of life medical and psycho-social issues remarks that “in the old days and when we didn’t have control we attributed things that happened to the will of God. Now, we’ve got choices and it’s not necessarily the will of God. And it’s the same at the end of life. We have the technology to choose, to be a little bit more in control of time of death – not perfectly, but certainly a bit more.” In the following chapters we will explore how this necessary choice is negotiated by advocates of assisted dying.

Chapter 2 – Assisted Dying as Spiritual Concern

If we define spirituality as being the form of practices which postulate that, such as he is, the subject is not capable of the truth, but that, such as it is, the truth can transfigure and save the subject, then we can say that the modern age of the relations between the subject and truth begin when it is postulated that, such as he is, the subject is capable of truth, but that, such as it is, the truth cannot save the subject.
(Foucault 2005, 15)

Guiding this research has been the desire to see how assisted dying could be perceived as creating the space for a good and meaningful death. For months following my mother's death, hardly a day would pass without some well intentioned family member/loved one/acquaintance imploring me to trust that God was in control and had a purpose for the timing of her death. Certainly not readily apparent, this purpose may never be revealed, but should nonetheless be understood as an undisclosed reality. However, as Barbara reiterates toward the close of the previous chapter, this perspective toward death and dying is no longer a necessary one. Rather, exponential investment in biomedical technology has opened a space for human choice and allows individuals "to be a little bit more in control of time of death – not perfectly, but certainly a bit more." Whereas, for some, the supernatural had long been privy to the power over life, death and dying, (bio)medicine's burgeoning gaze from the late 19th century onward slowly began identifying spaces for human intervention at the end-of-life. Manmade biotechnologies, such as the ventilator, help to trace out the contours of our life extending desires. But the flipside, as we have seen, has been a (re)emergent concern with what exactly constitutes death. Though originally framed in terms of the difference between brain death and cardiopulmonary death, this contestability gradually spread further into the value of a variety of end-of-life forms. Choice at the end-of-life became not only possible, but for many necessary.

In many ways, opponents to assisted dying, such as the bioethicist Margaret Somerville, could agree with this reading of choice as they recognize the choices made, typically resulting in death, when entering hospice or palliative care. The concern for Somerville and others, then, derives from a place less troubled with whether or not this choice exists (or is necessary), than from the perception that assisted dying indicates a choice strained through a materialistic, scientific rationality where human life lacks intrinsic value. To be fair, several advocates do readily admit to embracing this approach. That being said, however, the question could be asked whether or not one's support for assisted dying requires such a rationality? At its heart, this chapter works through this very question. To do so, we will begin by addressing the way in which Somerville's concern ties into a larger critique of modernity – a critique focused around modern disillusionment, disenchantment and the resultant lost sense of meaning or purpose. Though several proponents may indeed support assisted dying from such a perspective, the second half of this chapter teases out at least one alternative approach located around various intersections along the complicated vectors of spiritual and material concern. For the advocates working through this perspective, it will be shown how assisted dying is utilized as a Foucauldian technique of the self geared toward spiritual transformation.

Solo Rap Battle

May 13, 2015. I am in Brockville, Ontario (a town about an hour south of Ottawa) at St. Paul's Anglican church with my friend John, 71, and his wife, Linda. We are sitting about three or four pews behind the panelists for tonight's Spring Seminar entitled "Living Well, Dying Well: The Church, Palliative Care and End of Life Legislation." That morning I had arrived in Brockville early enough to attend St. Paul's weekly "Healing Prayer" ceremony thinking that it would be an insightful experience with John in light of his interest in assisted dying. When he and I met a month

earlier at a Dying with Dignity training session in Ottawa, I was intrigued by his stated interest for attending – to learn more about the “spiritualism of assisted dying.” Though the training session had hardly touched on it back in April, our conversations since often returned to the dichotomy between his unshakable belief in God and evolution as an advocate for assisted dying.

As we sit there, I cannot help but feel a bit uneasy for John. Retired from his UPS franchise, John spends much of his time volunteering for St. Paul’s as a Lay Reader and fulfilling various other positions around the church. Earlier that morning, John told me there was a strong possibility he would be coming “out of the closet” as an assisted dying advocate tonight. Seeing as though both of the night’s panelists – Dr. Ivan Stewart, a professor of Palliative Care at Queens University, and Dr. John Patrick, the President of Augustine College and retired professor of Medicine – are avowed opponents of assisted dying, I am worried he chose the wrong crowd to come out to. And to think, it is probably my fault. A few weeks earlier I had asked if anyone aside from his close friends and family knew of his involvement with Dying with Dignity or general support of assisted dying. At the time, the answer was no. Though there have been several times that he has felt the urge to discuss it with his Bible study group, he has been reticent since “I’m operating under the assumption that they’re in that group that want to put [acknowledging death] off as long as they can. So they’re going to react with horror at the fact that I’m saying ‘Hey, you’re going to die.’”

So, we sit there, I anxiously and he ... well I’m not really sure. And though the context for tonight’s panel has been loosely framed as a conversation around palliative care, as Dr. Patrick begins his presentation he offers a rather vitriolic polemic against assisted dying. Wedged somewhere between his proof that euthanasia indicates a failure of moral conscience and resembles the genocidal activities of Nazi’s during the Holocaust, Dr. Patrick heatedly “reminds” the

audience that “reductionism is at the core of the euthanasia debate. But when you’re sick, there’s much more to you than biochemistry!” The staccato emphasis and directness of this comment is jarring, though not surprising. Actually, as a common objection from opponents, my participants and I often find ourselves addressing this argument – does supporting assisted dying require the belief of human life as reducible to biochemistry?

As we gradually move into the Q/A period, several questioners are concerned with how the recent Supreme Court decision striking down the ban on assisted dying will affect their own lives. Still others wonder aloud whether or not those in support of assisted dying should be added to their prayer lists. And then it happens. John stands up, states his involvement and proceeds with his question “what is the psychological difference between physician assisted suicide and palliative sedation for the remaining family and friends?” Ostensibly suggesting once again that assisted dying is murder, Dr. Patrick hurriedly picks up the mic to dismiss John’s question saying, “if you take a drug that would achieve the same thing without death then you’re not killing. But if the end goal is death then you’re killing!” Without taking his eyes off of John, he drops the mic and pushes himself back from the table as if he’d just won some sort of rap battle.

Biomedical Disenchantment

Dr. Patrick’s repeated connections between assisted dying and killing is indicative of his overall sentiment that advocates hold human life with little value. Similarly, for Margaret Somerville (2001), the issue of assisted dying is deeply enmeshed within an emergent cultural paradigm of “pure science” in which human life becomes reducible to the product of biological machinery (ibid., 7). Warranted or not, Somerville’s concern is not without precedent. Indeed, a wealth of literature points to the way in which we are increasingly growing to understand ourselves through various biomedical or neurobiological knowledges. The sociologist Nikolas Rose talks

about “Neurochemical Selves” (2003) and argues that we are increasingly understood as “somatic individuals” – “beings whose individuality is, in part at least, grounded within our fleshy, corporeal existence and who experience, articulate, judge and act upon ourselves in part in the language of biomedicine” (2007, 26). In other words, we moderns increasingly understand ourselves in terms of biomedical knowledge. Somerville’s concern then, is that this biological reductionism confines human life and removes any “space for spirit”, “intrinsic value, mystery or meaning” (Somerville 2001, xiii). Though careful, if unsuccessful, to cleave this “space for spirit” from its religious cognates, Somerville operates on the assumption without such, human life will be readily subsumed into the mentality of consumer societies in which objects that are worn-out are seen as useless and to be discarded. The loss of cognitive or physical functionality whether due to age, illness or accident places the pressure to “get rid of” on that life. Assisted death is the inevitable and unenviable result of such a world.

Offering a similar, though less apocalyptic, critique, the sociologist Shai Lavi (2007) traces out assisted dying’s emergence as concomitant with “human beings’ [desire] to master their world for the sake of mastery alone” (ibid., 179). Treated in no small way as a modern addiction to being in control, Lavi’s claim is that our quest for mastery has left us stripped of freedom and subordinated to the rule of technique. Rather than distancing ourselves from the growing prevalence of biomedical tedium at the end-of-life as maintained in the previous chapter, Lavi sees assisted dying as incorporated within the very same logic. Biomedical intervention battling biomedical intervention. And though his critique does allow people to continue following various laws of tradition or faith in their private lives, as a larger society “we have become defenseless in our confrontation with the technical laws governing the deathbed” (171). Regardless of our private beliefs, we are altogether subsumed within the rule of technique while simultaneously being reliant

upon and repulsed by its necessity to attain the good death. Or, as Singh and Rose ask, “can individuals resist/access the pharmaceutically powered drive toward perfection?” (2006, 97).

Perhaps this is what the philosopher and feminist scholar Donna Haraway meant by “technoscience is a millenarian discourse about beginnings and ends, first and last things, suffering and progress, figure and fulfillment” (1997, 10). Technoscience, of which biomedical technology forms an influential subset, is really a discourse about salvation. As biomedical technologies are created, rationalized and implemented with the “prime function of enabling humans to act on the world and its people” (Lock and Nguyen 2010, 20), they take on problems such as sexual dysfunction (Fishman 2010), ageing (Hoberman 2006; Watkins 2007), or reproduction (Mamo 2010) and reframe them in terms of hopeful potentiality (Taussig, Hoeyer, and Helmreich 2013, S4). That being said, these technologies are not simply objects free from valuation. Rather, as we have seen in the last chapter with the artificial respirator, biomedical can “change us, and even as they themselves are constantly modified, they change the world in which we live” (Lock and Nguyen 2010, 20). Clarke et al. even suggest that the technologies of biomedicalization “extend beyond merely regulating and controlling what bodies can (and cannot) or should (and should not) do to also focus on assessing, shifting, reshaping, reconstituting, and ultimately transforming bodies for varying purposes, including new identities” (2010, 78). We are supposed to want to take on new biomedically mediated identities. And indeed there is a moral imperative to do so: “‘wellness’ – the avoidance of disease and illness – has become a ‘virtue,’ for some, a secular path to salvation” (Lock and Nguyen 2010, 28). Thus, in this way readily assume a salvational ethos in which application upon application upon application become necessary to achieve a variety of needs and desires.

But what happens when the end of life is obviously there? If wellness has become a virtue and for some a secular path to salvation, what does it mean when one is unwell? What happens to salvation when it no longer becomes possible to be well and avoid disease or illness? Lavi suggests it is again at this point that we return to the technology that has so long been our savior. If this is the case, then Somerville's concern may not be too far off center.

In his famous lecture to German graduate students, *Science as a Vocation*, the sociologist Max Weber asks a rhetorical question: "What did science mean to these people on the threshold of modernity?" (2015 59). For Leonardo Da Vinci, science could have meant the path to true art (ibid.). Science was the way to nature. Science was the way to creating. How incredibly ridiculous this would sound to someone today, he suggests. "Apart from overgrown children who can still be found in the natural sciences, who imagines nowadays that a knowledge of astronomy or biology or physics or chemistry could teach us anything about the *meaning* of the world? ... If anything, the natural sciences are more likely to ensure *that* the belief that the world has a "meaning" will wither at the root!" (ibid.). Science is particularly separated from meaning, value and especially from God. So, he asks "what is the meaning of science as a vocation now that all these earlier illusions – "the path to true existence," "the path to true art," "the path to true nature," "the path to the true God," "the path to true happiness" – have been shattered? The simplest reply was given by Tolstoy with his statement, "Science is meaningless because it has no answer to the only questions that matter to us: What should we do? How shall we live?" (ibid., 60). If Weber is right, then it is possible to ask how advocates of the assisted death are seeking a meaningful death via biomedical (read scientific) procedure. From the time that I have spent with several advocates, it is my understanding that for many, the desire for an assisted death is not some nihilistic plea to a world lacking any meaning or purpose. While advocates of the assisted death continue to maintain

a pragmatic connection to biomedical technology, those whom I spoke with refuse to look at it as a figure of salvation. Rather than reducing life to mere material presence to be subsumed within biomedical procedure, many of the advocates I spent time with struggled with spiritual concerns as a way of making their dying meaningful. But before seeing how this might be done, we will look quickly at the way in which Somerville's description of assisted dying advocates as individuals coming from materialistic, scientific rationalities is not completely wrong.

Materialism in action

Somerville's concern is that assisted dying embodies a meaningless death. Death and dying once taught us values about living, but that we now entertain the thought of accessing an assisted death before dying "naturally", it is as if we believe there is nothing more we are trying or able to learn. In this way, assisted dying is seen as a negative result of the emergent cultural paradigm of "pure science." Death no longer offers any insights or future to the dying (not to mention living) person, but rather represents the simple expiration of biological life. Much of the public discourse surrounding the right to die focuses on materialistic concerns. And there is nothing wrong with this, but it seems to prove Somerville's point that assisted dying is that which discards human sanctity in favor of biological concerns.

For Beth, a 78-year-old retired technical writer for parliament, this is precisely the case. Throughout her life, Beth has had a lot of experience with people dying. As we sit at the dining room table in her small, somewhat cramped apartment, she tells me she has even had someone die in her arms. Without wanting to go into the details, she tells me that holding this person as they died was actually "one of the most peaceful things I have ever seen." And while she admits that this was not a long and drawn out dying period that she fears, the almost imperceptible shift

between life and death, “one minute he was alive, one minute he was dead but there really wasn’t any other change,” does not scare her as she knows that this is just the way life goes.

When I die, I’m dead. I don’t see my soul floating up to heaven. [...] No, when I die I’m just going to die and I won’t be here anymore. [pause] Well no, I’ll be over in the Ottawa hospital (laughter), or the university. [pause] The University of Ottawa Medical School has a mini med series that they run every spring and fall, so I’ve gone a number of times and one of the times we had the option to go to the lab where they keep the bodies. We looked at bodies and the guy explained “this is there, this and this are there” – all that sort of thing. A woman fainted. But wasn’t that gruesome. [pause] It’s just what happens. I don’t find it all that bad.

Though Beth still contradicts Somerville’s belief that those interested in assisted dying are actually afraid of death, her understanding of what happens at death is not uncommon. She tells me elsewhere that for years she has told her family that if she is ever diagnosed with a degenerative disease that she “doesn’t plan on sticking around.”

Kathy, 70, holds a similar sentiment as Beth. Though we are currently sitting in her living room sipping on coffee, she and I had met a few days before at a Dying with Dignity meeting in which a video was aired detailing the final days of a man with ALS. In this video, the man could be seen struggling to make it up the stairs, breath or even enjoy time with his family. As we talk, I invite Kathy to reflect on this video and place herself in a similar situation. “So I guess he just got to the point where he couldn’t breathe. That’s a scary thought though. Suffocating. For me, sometimes I wake up in the middle of the night, I guess I have sleep apnea or something, you wake up and you’re gasping for air. And I guess the thought of that being like a daily occurrence like as you’re awake and conscious that would be terrifying.” Ultimately, the man in the film died as a result of his inability to breathe, but Kathy says “I don’t know how he did it.” She questions how he could have continued to see value in life when there was nothing that he could do any longer “if that was me, I’d be, I’d be taking a pill.”

From the examples of Beth and Kathy it is possible to understand how Somerville and other opponents to assisted dying could perceive death and dying as purely materialistic concerns. But, as we will see momentarily, there are others who work through these situations with some sort of guiding thread other than their own bodies. This is not to say that suffering, pain and futile care are not concerns for these individuals, but simply that they are not their primary concerns.

What If ... ?

This section touches on the way in which many advocates bracket off life as lived from biological life as ultimate value by questioning “what if” something else had occurred in the dying processes of their loved ones. While it is true that similar to Kathy and Beth above, those advocates with some sort of spiritual belief share a concern for the degradation of their physical bodies, these concerns are often placed on the backburner. Rather than being focused on the end goal of achieving the assisted death, many of these advocates are attempting to negotiate what it means to be alive. It’s not so much what one is, but who, and potentially even how, one is that matters. “What if” simply tells the story of being forced to see life as other than the ultimate value.

In her work with Inuit youth and suicide in Nunavut, anthropologist Lisa Stevenson talks about the way in which presuming some inherent value of life or staging life as the ultimate good could become “as dangerous as negating it” (2014, 10). Only once she learned to “hold life as a value in abeyance could the outlines of a more indistinct, darker perhaps, and definitely more uncertain way of thinking and caring come to the surface” (ibid.). This idea of bracketing off life from living is something that a lot of my advocates have learned by experiencing the horrific deaths of others around them. If the potential of biomedical technology and the related moral imperative of wellness is understood as something that presents itself as a secular path to salvation, assisted

dying tends to question what happens when death becomes imminent. A breaking point does appear – there is a place where care becomes futile. At this point the trappings of a salvational biomedical technology seems to drop away. Many of the advocates have been forced to ask themselves if there is an absolute and inherent value to life. Here is just one example.

For the most part, John has lived an extraordinarily healthy life. Aside from several serious allergic reactions that landed him in the hospital as a child, he has rarely been in ill health through much of his life. But now 71, he's undergone several individual surgeries removing so many organs that his children joke all that's left to remove are his ovaries. In light of these recent hospitalizations and various experiences with his parents in the past, John says "I've begun to be concerned then about what would happen *if*." He takes this a step further by recounting the two stories of his parents' deaths.

Dad received a phone call one day and went looking for mother, couldn't find her and went downstairs and found her lying on the basement floor. And we still don't know, but I suspect it was a stroke. [...] But with the stage of medicine at that point they brought her back. Mother's greatest fear was not being able to be active in her life. She was an avid gardener, loved to read and loved to watch intense television – not the frilly stuff. And when she came out of whatever it was that they brought her back from, for the rest of her life, her vision was like the film in the old movie projectors that skipped the socket and was flickering. She could never concentrate on anything. She couldn't read. She couldn't watch television and she couldn't go out and garden.

Mother often said to me "I'm not afraid of being dead, but I am afraid of dying. The process of getting there." And she used to call the nursing homes "God's waiting room." Many times she would say "I can't face that. I don't want that prolonged dying and I want to be active. I can't live without being active. So if I ever face that, kill me! Mercy kill me." [pause] So what did we face? We faced mother in a hospital begging me to kill her. I said "I can't do it. I'm young. I have a future ahead of me and I'm not going to have any of that if I help kill you." The second thing that mother was fearful about is that she did not want to die alone. She wanted somebody there with her when she went through the process. It took 2.5 years from the time that dad found her on the floor until she died. [...] There was nobody there. Not my dad. Not my brother. Not me. Nobody was there for her when she ultimately died [...]

Within six months of her dying, on my dad's birthday, the doctor told him that he had prostate cancer and maybe six more months to live. So, they put dad on chemo. [...] I went down to Toronto for a job interview, went early and took the time to go to the hospital and see dad on the day of my interview. But I didn't leave myself enough time. I talked to him and as I was leaving the hospital room, I said "hang in there dad." And he just looked at me and said "I want this to be over." He died that night. I didn't have the presence of mind to turn around and say "It's okay. If that's what you want, it's time to go." And so I live with the fact that the last thing I said to him was "hang on" when he didn't want to.

John's mother felt as though life was no longer valuable once she lost her ability to focus on the things she once loved. What would it have meant if John had helped to kill his mother? His father was ready to die, but all that John could respond was "hang in there." What if he had told his father that it was okay for him die? Thought not obsessive, John does admit that he is burdened with the guilt of these what ifs. Imagining a different scenario, is for him what assisted dying is about. Part of the way John approaches the issue of assisted dying is by drawing upon the stories of his parents' deaths. Contrasting Somerville's statement that assisted dying is not only a failure of imagination (mystery, wonder, etc.), but also a material answer to a material concern, John wonders whether or not absolute opposition to the assisted death is not the failure of imagination. Is there a breakdown in their ability to see the possibilities of response? More specifically, can they see anything other than the breathing human as valuable? Or, even further, "is it because they're in the moment?"

Though I fail to confront this at the time, this question is curious. What would it mean then to be living outside of the moment? In his book *A Secular Age*, Charles Taylor talks about Secular Time as that which imposes on the bearers the necessity to "do something." Taylor talks about the secularization of time which puts "a premium on constructive action, on an instrumental stance towards the world" (2007, 541).

Our lives are measured and shaped by accurate clock-readings, without which we couldn't function as we do. This thick environment is both the condition and the consequence of our far-reaching attempt to make the best of time, to use it well, not to waste it. It is the condition and consequence of time becoming for us a resource, which we have to make use of wisely and to advantage (Taylor 2007, 542).

As the anthropologist Sharon Kaufman (2006) has shown in her book on the organization of death in American hospitals, contemporary death and dying have not escaped this necessity for accurate clock readings. Within the first page she writes that “this book is about time and death. It is about the bureaucracy, rhetoric, machines, and procedures that define American hospitals and structure time and death within their walls” (ibid., 1). Throughout the book she traces the way in which life's value is consistently measured and “open to endless negotiation” (ibid., 3). While everyone theoretically understands that death cannot be escaped, biomedical intervention localizes itself around this always already failed escape and “timing has become the crux of the matter” (ibid.).

But what happens when life and death are not envisioned as set on a linear progression of time. Another friend, Leah, a nurse in her mid sixties, once told me that “we're both alive and dying all the time. [... You could think of life as] a Mobius. So within itself is the beginning and the end. But where does it begin because there's no inside and there's no outside. Where do you suddenly start dying and where do you suddenly start living? [...] Inside, outside, inside, outside and becoming dead. And that unit is called living.” Dying has become too much a pressure of timing – too much about moments leading to death. What I think assisted death seekers are interested in is this freeing from the reality of our “lives [being] measured and shaped by accurate clock-readings” (Taylor 2007, 541).

Spiritual Belief

The secularization of time, as Taylor has framed it above, calls us to living within a perpetual state of doing – of using time “wisely and to our advantage.” In secular time one thing happens after another ad infinitum – once something has passed it has passed (2007, 55). Contrasting this to earlier understandings of “sacred” or “higher” which “gathered, assembled, reordered, punctuated profane, ordinary time” (ibid.), time as interchangeable, Taylor’s secular time flows only horizontally. Sue, a 69-year-old retired community worker whom I met at a Dying with Dignity meeting, worries that this cutting of life prevents us from paying attention to what really matters:

Sue: End of life isn’t just about medical care – it’s also about [pause] all those connections to family. It’s spiritual, whether you have any kind of spiritual practice or not. It’s a conversation with yourself. [...] I do think that our world has lost touch with a spiritual, a spirituality writ large. That we’ve become a very, what’s the opposite of spirituality?

Elijah: Mechanic?

Sue: Yeah ... so it’s all just about what you can see and touch and measure.

Elijah: Materialist?

Sue: Materialist. That we’re not attending to quality of life. We’re not attending to things that have to do with community, relationship, connection.

For Sue, and several others that I spent time with, what matters at the end of life is not this continual cutting of time into what can/should be done next. There are spiritual concerns that must also be attended to. Seen this way, rather than lumping all advocates of assisted dying into the simple category of materialist, it would seem more reasonable to approach them as humans negotiating the confusion between personal belief and biomedical availability at the end of life. On the one hand, we have the promise of biomedical technology to keep us alive. That being said, this also has the unwanted effect of keeping us alive long past what we find to be reasonable life. On the

other hand, we have our beliefs in the supernatural (God, Being, or simply otherwise) with which to negotiate. This is the predicament for several of the actors within the movement. What we can see in this chapter is the way in which the spiritual and the natural (meaning biological) begin to clash and how this is worked out for many of my advocates. While they can neither wholesale accept an assisted death nor one in which God calls all the shots, they see assisted death as a meeting point of the two in which what/how/who one is can be worked on.

Anne's dining room table is covered with stacks of newspaper clippings detailing both her decades long interest and active involvement in the assisted dying movement. Now 91-years-old, Anne began compiling this material nearly forty years ago following the Synod of the Anglican Church of Canada's 1977 Task Force on Human Life in which they raised the subject of "euthanasia for the incurably mentally deficient and for those suffering at the end of life." But as we begin talking over several cups of coffee that she swears will kill me, Anne admits that she began contemplating the value of life in these situations long before the Anglican Synod released this report. When she was in her early twenties, she and her husband had their first son, John. Born with Hydrocephaly, "his brain was more or less destroyed due to the immensity of the pressure. You should have seen these children [like him] – huge, huge heads. He had no sight, but he had an appetite. He could hear, I think. But he had no knowledge! No knowledge of anything at all. He was a physical [pause] something physically alive. [...] He was barely alive and I knew I wasn't doing him any services." So, unable to care of him in their home, Anne and her husband made the difficult decision to place John in an institution. Though some of the other children living there lived well into their teenage years, "they had no life." At the age of four, John contracted pneumonia and died. Over sixty years later, Anne still struggles to formulate this story. Her love for John was immeasurable, but she cannot help but wonder whether he was ever truly alive.

Though slightly uncomfortable with the seemingly eugenic direction of this conversation, I invite her to share more on her sentiments of “barely alive”, “something physically alive” and “they had no life.”

Elijah: So you see a physical “being-ness” in the lives of John and others with Hydrocephaly, but not necessarily an active being alive?

Anne: There’s lack of quality of life, I suppose [pause] and I’m flying in the face of established religions of any kind. All religions teach that life is sacred. Well [pause] life is sacred in so far as we should care for and respect each other as we live, but the preservation of a ruined life surely cannot be [pause] a Christian thing to do. To preserve a state of existence which is only giving suffering cannot be right. It cannot be ethical. It cannot be ethically right.

As a practicing Anglican, Anne admits to struggling with the dissonance between her faith in God and advocacy for assisted dying. For Anne, it is inconceivable that God would want the existence of individuals in such severe states of disability to be preserved. She clarifies that she does not condone the euthanization of infants as they do not have the ability to choose. Even so, I am reminded of a conversation with my father who tends to toe the line on a conservative Christian perspective toward assisted dying. As we talked he reminded me that throughout my mother’s final days, it seemed as though she was in a coma and without life. That being said, he believed that during this time it would be impossible for those of us surrounding her to know what could have been going on spiritually, mentally and emotionally. Perhaps, he suggested, God was using those final days to achieve something beyond our imagination. Whereas Anne seems to tie the sacred value of human life to our ability to physically inhabit that life, my father’s concern with human life seems to fall more within God’s omniscient plans. With this in mind, I push Anne to describe how she might reconcile these two perspectives. At first she is hesitant and describes her self as hypocritical, but she soon explains:

God never said that he was going to make everything perfect for us. God gave us life, but he hasn't told us what to do with it. God never promised you a rose garden. If God created the world and gave his life, I see him sitting back and saying, there you go, get on with it. He didn't put any [...] conditions on it. He didn't. He simply created life. Humans evolved and developed minds and became thinking creatures instead of unthinking creatures [...] We were given life to do with as we liked. So, my short answer on how to reconcile even mild religious beliefs of my own, in terms of assisted suicide and euthanasia, is that we were not given life on any terms. There were no restrictions. Of course, life should be preserved if it can be [but there is not sacred imperative].

In this way, Anne is expressing her belief that there are no hard-set, divine rules governing how we must live and die. But rather, she believes that we have been given life to do with as we please – to live creatively. That being said, of course, there are guiding principles which ought to orient our decisions, but these decisions have ultimately been placed within our hands. Or as John, who we met earlier on in this chapter, says “it’s not how you die that is important, but it’s how you live to get to that point of death.” John believes in heaven. He believes that there is life after death, but he cannot accept that death itself is sacred. In his Advanced Care Directive (a legal document detailing what he would like to happen were he to become incapable of expressing himself) John reminds whomever may be reading it that “birth is a gift from God; death is a certainty that comes with that gift. This does not suggest that death is a religious or even moral event; only one death was sacramental. Neither does it suggest that the process should be governed by my particular religious or moral beliefs. What it does mean is, that while life is precious and should be lived to the fullest, death is inevitable.” Life is sacred in that any life that still maintains a certain level of quality should be healed and kept alive, but there is nothing sacred in our deaths.

Praying for Life

John believes that Christianity, as well as many other religions, often place too much value on this life on earth. With such an understanding of life after death, he is surprised by the way in which so many “Christians, who fervently believe in life thereafter with the Lord, want to prolong as long as possible getting there” Though he carefully places assisted dying within a context of already at the end-of-life, rather than what he would assume to be the premature death of suicides, John is confused why so many Christians adamantly oppose assisted dying. “I don’t understand it. For some, they couch it in terms of ‘I’ll wait until the Lord takes me.’ But the Lord doesn’t take you! The Lord receives you!” And this keys into something that several advocates of assisted dying reiterate. Death, as such, is not life being taken from you, but rather something that “occurs”, “just happens”, or “we fall into.”

As an undergrad at the University of Tennessee, many Sunday evenings were spent at my campus ministry. Every Sunday, we gathered prayer requests and on one particular night we prayed for the healing of a woman who would most certainly be dead within a week. Afterward, I confronted my minister confused as to why we would ask God to prolong her life if we believed in an afterlife. Seemingly astonished by my question, he had no answer save God’s will would be done regardless of our desire. Though I hold this man with utmost respect, his astonishment that this question could be asked was surprising. Why would anyone not pray for life? I put the question to John who replies:

I personally never pray for extended life. One of the other elders, who is in the process of dying right now, made the point that there is difference between healing and getting better. You can pray for healing of the mind and body – that the person will come to accept the situation they’re in and work through it. This doesn’t necessarily mean that they will get physically better, but you can pray for that and I tend to do that. At times it has even shocked some of the other folks when I’ll say not our will, but thine be done. This is what we would like, but we’ve got to turn it over to you.

Moments earlier John had told me that the “Lord doesn’t take you” but now he prays “thy [the Lord’s] will be done”? Confused, I invite him to clarify these two seemingly opposed statements. Letting out a slight chuckle he admits that he is currently working out these very questions himself. That being said, he attempts to resolve the conflict by claiming that God neither creates nor causes bad things to happen as in the book of Job. “Nature, coincidence, all those things will create the bad things that you may find yourself in, but God is always there with you if you will turn to him for support.” So rather than God dictating how things come and go, he simply watches and allows us to explore for ourselves. We have our own free will to do with as we please

From this conversation with John, as well as the previous section’s conversation with Anne, a picture of an unresolved struggle between spiritual belief and material concern begins to emerge. While their faiths may have prescribed notions of what makes life sacred or how life and death should be prayed for, they find wholesale acceptance difficult. Indeed, nearly every individual I spoke with who held some sort of spiritual belief struggled with similar dichotomies. In *A Secular Age*, Charles Taylor attributes this inability to accept religious perspectives without question to a massive change from a “naïve” background of belief to a “reflective” one (2007, 14). Rather than belief tying one to a singular point of identification, belief now becomes one option among many – faith in God, “even for the believer, is one human possibility among many” (2007, 3). The point being not that there is no more belief in God, but that this belief is constantly open to examination. Or, as Rabinow has written elsewhere, “anthropos is that being who suffers from too many logoi” (2003, 6). Thus, rather than lacking a sense of wonder or shared mysticism with life as Somerville and other opponents assert, activists find it difficult to take these feelings for granted.

Suffering and its Discontents

Initially, when Sue's father was diagnosed with both Parkinson's and Alzheimer's, he decided that life would no longer be valuable and that he "wanted help leaving." As this was a decade before the 2015 Supreme Court ruling legalizing assisted dying, several back ally channels had to be followed before eventually meeting with members of the Right to Die Society of Canada. Though several weeks were spent working through the exact process of the death and learning which days the police would be less likely to investigate the death, Sue's father withdrew from the process. She says that regardless of all of these preparations, her mother worried that either herself or one of her daughters' would be arrested on suspicion of murder. If he followed through with the plans, neither his wife nor their daughters were allowed to be present. Within days of the planned death, Sue's father opted out saying, "if my wife is not going to be there, I'm not going there." Instead he chose to continue living and "tragically" lived another two years in a nursing home before dying.

Even though her father ended up not acting on his desire to die, Sue was conflicted with the whole idea. As a practicing Nichiren Buddhist, she turned to some senior members of her Nichiren community for advice. But as there are no hard set commandments as is the case for most monotheistic religions – aside from "the law of cause and effect" – one woman told Sue something along the lines of "we have tools in our Buddhist practice, to help us sort out and be clear about what's right and what's important and what we ought to do." Nonetheless she explains Buddhism maintains that all life is precious – what should be done then? Having watched her father live through both Parkinson's and Alzheimer's she cannot accept that all life is precious. Instead, acting as a non-restrictive guide for her thoughts on assisted dying, Sue draws on Buddhist practices of being conscious and present within the moment, as well as Michael Singer's conceptualization of

mindfulness and presence within his New York Times bestseller, *The Untethered Soul* (2007). In this way, the best thing that she can do is to work on herself and make herself capable of accepting (accessing) the truth.

To elaborate on this, Sue works out a conceptualization of suffering and its value or purpose at the end-of-life. Though she initially begins by saying that she hopes it is not necessary, she stops herself short. “If we lived a life without any suffering, without any pain, we’d end up as pretty shallow people. [...] Whether we talk about it as pain, suffering, a challenge or problems [pause] I’m of the philosophy, which is linked to my Buddhist practice, that they are opportunities. They are opportunities. And how we meet these opportunities defines, in a lot of ways, who we are and how we are.” Suffering has the capacity to be transformative, even at the end-of-life. Sue recently watched a documentary on Irena Sendler, a Polish social worker who played a major role in the Polish Underground that helped hundreds of Jewish children escape Nazi occupied Warsaw. Eventually captured by the Gestapo, Irena was tortured and nearly executed for refusing to give up the methods and co-conspirators of the Underground. Amazed, Sue reflects on Sendler’s ability to remain steadfast throughout such excruciating circumstances: “She must have been very clear, and able to be present, in her determination to protect people.” Suffering, for Irena, transformed to lives of those children who were able to escape, but this positive value of suffering cannot detract from negative suffering as well. Referring back to her father’s situation with Alzheimer’s, if she is without the “strength of mind to be conscious of how we want to be present [throughout our suffering]” does she want to linger, “or do I want to leave?”

For Sue, physical suffering is not a contributing factor in her support for assisted dying. Rather, she draws on her Buddhist foundations in acts of presencing and being conscious to express concern of living a fulfilling death. And this rejection of materialistically based suffering as

impetus for assisted dying is something that many of those I spoke with insisted upon. When Karen, another woman who introduced herself to me at a Dying with Dignity meeting, and I met for coffee, our conversation soon turned to suffering at the end of life. Though she outright rejects that pain and suffering have any intrinsic value as some belief systems maintain, there are times where suffering can be a powerful tool for self-awareness. Similar to Sue's connection with suffering and activism, Karen wonders at the strength of Civil Rights activists in the 60s and their ability to continue risking beatings, harassment or even death for their purpose.

Karen believes in a Higher Power that is of her own choosing and interpreted in her own way. What Higher Power wants for her is not that she suffers or lives in pain, but rather that she has a "life that is fully lived." Sometimes this would mean that suffering has value, but at others it may not. "Suffering happens, but so does joy. Pain happens, but so does ecstasy." In this way, suffering and pain are intimately tied to more positive feelings of joy and ecstasy. There are multiple factors that make pain, suffering and whatnot worthy of continuing. "A life fully lived is the best that I can count on."

I read something the other day that I think expresses my thought on it, it is that you can either live until you die, or you can die until your dead. [... And] you can live your illness fully. I experienced that when I had cancer. Man I'll tell you, my illness gave people an opportunity to help. They cooked my meals. They took me to my appointments. They went to the doctors. They made sure I got out and went to movies. And I'm not saying that my cancer had a purpose, but it was an opportunity for people to do their best. And if at the end of my life that's how my living looks, maybe that's not so bad. [...] As I think of it now, I would perhaps be in pain and losing my faculties and yet at the same time, as I found with my friend who was in the hospital, she could still look out the window, even in the last week, and say "by golly, there's some birds there!" And so she was, as best as she could, she was living, even though she would be dead within a week. [...] I think that being alive is a daily, and even a momentary opportunity to live fully.

Somerville's concern was that those who advocate assisted dying also envision life as merely the sum of biological functions. As such, paired with extensive suffering, once these functions

began to dissipate, so would the desire to live. However, as evidenced above and below Karen strongly opposes this idea.

So, like everybody else I have some down days. I'm not ill and I'm not expecting to die any time soon, but I do have some down days. But I am able to step back and say, 'Now wait a minute here. Let's put this in context. Look at the good things that happen.' This is not going to hold me up at night because I know that I'll have another opportunity tomorrow to live fully. If you're on the verge of dying you may not have that. I don't know what to do about that philosophically – what to think about that.

And that is where we left that conversation. She was unsure. What do you do when you're dying and you no longer have the opportunity to live fully the next day? And that's where many of the people that I spoke with end up. At some point there is such a thing is incapable of living fully.

Chair of Transformation

Sue asks whether or not a lost sense of presence at the end of life would make her want to die. Karen cannot answer what to do philosophically when you may no longer have those opportunities to live fully at the end of life. This uncertainty was pervasive. As we discussed toward the opening of this chapter, biomedical technologies offer ready made salvation from these uncertainties. Or, as Lavi argues, assisted dying is a technique subsumed within further technique and that is the best that we moderns can hope for. But, the further my relationships developed with these individuals, the less I could be convinced that assisted dying always meant quick, biomedical salvation from suffering.

As Gandsman, Herington and Przybylak-Brouillard (in press) have recently drawn out (and has similarly been demonstrated above), for many assisted dying advocates, interest stems from their own involvement in the dying process (and in most cases, death) of a family member, friend or even patient in the cases of healthcare workers. Having witnessed a variety of horrific deaths, many became concerned with not following similar paths in their own dying. Thus, rather than

sitting passively waiting for death, Gandsman et al. utilize Heidegger's notion of being-toward-death to demonstrate how many advocates seek to embrace death's approach as a way of making the lived life more meaningful and to reclaim a lost "art of dying." With this goal in mind, it is possible to ask what are the ways in which assisted dying actually helps reclaim this lost art?

Toward the end of his own life, the philosopher Michel Foucault became increasingly concerned with the way in which a "human being turns him- or herself into a subject" (1983, 208) and the related ancient Greek concept of "gnothi seauton" or the care of the self. In the introduction we briefly worked through Foucault's four aspects of the "care of the self": ethical substance, *mode d'assujettissement* (mode of subjection), techniques of the self and telos – the desired outcome. It is my contention that assisted dying is, in a sense, about the care of the self. The ethical substance being worked on is that of dying. The mode of subjection is what Gandsman et al. have drawn out as "being-towards-death" and the desired outcome is the good death/lived life. But to achieve this good death, work must be done to the self – there must be a transformation of the self. Foucault calls these necessary transformations the practice of spirituality. Unlike the "modern age" where truth (in our case the good death) can be accessed by knowledge alone, "spirituality postulates that the truth is never given to the subject by right" (Foucault 2005, 15). Thus, rather than simply facing death, it could be seen as a practice of the self to make lived life more meaningful.

As a psychotherapist operating as the Personal Support and Advocacy Coordinator for Canada's premier right to die organization, Dying with Dignity, Nino has become intimately familiar with the stories of hundreds of individuals seeking navigational insight on the potential traumas surrounding end of life. Perhaps unsurprisingly, we've been talking about me for the last ten or fifteen minutes. Sparked by my involuntary opening up about the residual pain of remembering the sullen words "I hate you!" spoken at my mother the last time we would ever talk,

Nino's telling me that the perpetual revisiting of this "trauma" will forever be a part of the necessary work in my own development as a person. "It will need to be metabolized somehow and incorporated into who you are at that moment twenty years from now, or even now." The involuntary goosebumps running the length of my spine tell me there may be something powerful couched within these words that will perhaps provide insight to an emergent theme I had not previously anticipated. Nonetheless, I feel we're straying too far from our larger conversation on how the assisted death potentially creates a more meaningful space for the dying process and attempt to bring us back around. Recurrent metabolizing of traumatic events and development as a person – how would he tie this to assisted dying movement? I ask him whether or not it is necessary to have previously experienced some sort of traumatic encounter with death before we are capable of understanding assisted dying?

Maintaining course, Nino invites me to think less in terms of how to understand the movement as a whole but to remain within this emotionally charged space of trauma and ask how it intersects with dying itself. He tells me that the sheer presence/remembrance of a traumatic event (not necessarily someone else's death) tends to prevent people from approaching death positively. If death cannot be approached positively, we cannot learn anything from death. Thus, taking his cue from spiritual activist and teacher Stephen Jenkinson, Nino wants to look more into what death is trying to teach us at the end of life. Whereas he believes that Jenkinson already operates within a semi-ideal world where death can teach us something without requiring anything but acceptance on our own part, Nino believes that this staircase to this world is broken. There is no way that people living here today would easily allow death to "naturally" teach us something. When I press him on this he takes a long pause and says:

Because you simply have huge numbers of traumatized people for whom [...] they don't want to fucking hear about it. Because the trauma is so deep – and when I say trauma, I mean meeting your fears, your shame, your humiliations, meet stuff, unpleasant stuff, not pleasant, but unpleasant stuff – for some people, the amount of unpleasantness and shit that they've gone through in life is simply not workable. You would just re-traumatize, you cannot push people into working on their own trauma. They need to be in the place where they feel ready to dip into that. [...] There is a myth, I'm sure you've heard, of King Arthur and the Knights of the Round Table. In a very old version of that myth, there was a chair around the round table on which no knight ever sat because it was too fucking dangerous of a chair for anyone to sit in and these knights were guys who did everything! The name of the chair was Chair of Transformation. And the guy who eventually sat on it was Galahad – the guy who found the Holy Grail later on. So that tells you that the internal transformation is a much harder and a braver thing to do than any shit that these knights did on a symbolic level. So you cannot push people into that. But I think assisted dying can, maybe open the door or open the window, or ... take away the veil to different degrees with different people. That's why I think, essentially, legislation is a good step on that staircase.

If, like Jenkinson, we are interested in the question of what the end of life is all about, it will take work. Much like the way in which Foucault formulates how truth was conceptualized up through the sixteenth century – “truth always has a price; no access to the truth without asceticism” (Foucault 2010, 371) – it is going to take a spiritual transformation of sorts. Having reread the relevant parts of Sir Thomas Malory's, *Le Morte d'Arthur*, I'm not entirely sure which legend of King Arthur and the Knights of the Round Table Nino is familiar with. In Malory's version (which seems to have been the first published in 1485) this Chair of Transformation is written in as the *Siege Perilous* – the perilous chair. Galahad, the knight who is eventually able to sit in this chair is preordained – the chosen one. It is prophesied long before he sits that he will be the one able to sit in this chair. What is more interesting than Malory's version of the tale of the *Siege Perilous* is the way in which Nino reworks it and turns it into a practice. It's hard and it's dangerous to sit on this chair of transformation, but there is a reward. Galahad was the knight who found the Holy Grail. And when he reflects on Jenkinson's question of what is death trying to teach us he is making it to where it is only possible to access this truth, this teaching, by embarking on the enterprise of

taking care of oneself – of transformation of oneself. Once we are able to address ourselves and work through ourselves, that is when we will be able to access the good and meaningful death.

Shelley, a hospice intake coordinator in British Columbia, draws upon her personal interpretation of dignity to reflect a similar interest in approaching dying as a transformative process. Throughout our conversation she calls on dignity several times without ever fully clarifying what is meant. And though ambiguous “dignity talk” (Gandsman and Burnier 2014) is common throughout the movement, I invited her to demonstrate how she would apply it to assisted dying. For some, she explains, dignity is understood externally – as something along the lines of having your bottom cleaned or needing help showering. But for herself, dignity is an internal quality. Something that cannot be influenced from the outside. Opponents to assisted dying similarly call for an internal understanding of dignity that recognizes the intrinsic value of being human, but Shelley’s inner quality relies less on intrinsic universals rather calling upon and active participation of the individual. She clarifies that dignity is:

not something that is or is not happening – it’s about an inner quality. I guess the other word I would use is being at peace. Being at peace, or being in acceptance, doesn’t mean that they’re in total agreement with everything that’s happening – but they’re not fighting it. It means that they’re part of the process instead of pushing it away. Dignity becomes about someone’s ability to just be in their situation.

Becoming part of the dying process rather than fighting or pushing it away. Rather than being an intrinsic quality of humans, dignity represents the work of transformation at the end-of-life. As if to drive this point home, Shelley shares the story of a friend and former hospice patient. Only in her forties and with twin 16-year-olds at home, her situation was incredibly difficult. Shelley’s frequent visits were filled with sadness, and within two weeks her friend had died. As she recounts a few of their final conversations, she remembers the times her friend would occasionally wake up believing that she had been healed and was no longer near death.

The hard realization immediately following these occasional moments of relief forced a return to the space of acceptance and what could be done now:

Her hope became about what conversations she could have with her kids before she died. And then her hope really just became about really not spending too long in the way that she was because it became hard. There was such a peaceful quality to her. There was a quietness [pause] and a dignity. Even though she would have chosen to get better if she could have. Acceptance doesn't mean that you like what's happening. Just that you see it for what it is and you incorporate that reality into how you're going forward in your life.

Valued above all else is this ability to accept what is happening to you and move forward. The worries, pains or fears of dying hardly disappear at this time, but rather than resigning yourself to fate or fighting against death at all costs, there is a need to continue acting creatively. Whether or not there is some hope for becoming physically better is not the issue and takes the backburner for Shelley. And this is not an individual procedure, but one in which the entire continuity of care is called upon to share. Working on yourself to be at peace in your situation. Not necessarily giving up, but working on yourself to accept and at the same time trying to move against it.

In the week following our conversation, Shelley felt as though she had not thoroughly described what she meant by dignity and decided to email me stating further that "I had described dignity as an internal state, but I think the idea of dying with dignity is one that encompasses our ability to have choice about what and how things happen with us, and when we're dying there's often so very little we have choice about. Maybe knowing we have choice takes us a bit closer to that internal state." Assisted dying in and of itself is not the goal for some of the advocates that I spoke with. But what Shelley, Nino, John, Sue and Anne have worked out above is that assisted dying may more be a spiritual technique of the self rather than a technique to achieve a technical ending.

Chapter 3 – Others

The word and the history are only paper. But the experience, especially the experience of suffering. Open your eyes and ears, open your door, open the leaves of your table, open your heart, open your homes, your arms. Open what the philosophers most often seek to close.

Everything but the mouth. Give what they hold back.

(Michel Serres 1982, 9)

In the previous chapter I laid out the way in which Somerville's concern for assisted dying as a failure of scientific and materialist rationalities can be contested, and often is, by advocates within the movement. Nonetheless, as a technique for the practice of the self – the spiritual transformation of one's self – it could be argued that there remains a deep seated concern for oneself. Indeed, the second of Somerville's worries with assisted dying that we will address is that assisted dying is the result of modernity's turn toward an "intense individualism." Such an individualism, she maintains, reduces our search for values to the simplicity of what is preferred by each individual making it difficult to find a consensus with which to "form a community and protect the common good" (Somerville 2004, 8). This failure of consensus on the common good and sense of community, when turned onto assisted dying, breaks the bonds between individuals and mutual respect for the other's life. As I traced out in the introduction as well as the previous chapter, Somerville envisions a resultant wholesale loss of care for dying individuals in which they are systematically killed or neglected to the point of death as they are seen as without value. But what happens if the dying already feel neglected and left to die?

While Somerville and opponents are not wrong when arguing that the issue of assisted dying often arises from an intense sense of concern for one's self, what they fail to consider are the ways in which concern for others can be expressed in parallel to these concerns for self. The following chapter will trace out these concerns and show how the story of assisted dying advocates is not always just about "me." Beginning by demonstrating how advocates often depict dying as

an already lonely process removed from community, we will then work into the way these lonely deaths have affected them before finally seeing how many desire their dying to be much more connected and capable of telling a story of living.

Keeping the Water Safe for Swimming

Cautiously slipping past the blinded window, the light slides quietly around the eighth floor Toronto office seeking something with which to become more than nothing. Encountering walls, it barter trajectory for form. Relation becomes established. Walls rush outward from their immobile forms while the light clings, lichen-like, to their porous skins. Walls becoming space; light becoming form – light-wall, wall-light. Dim with a slight tinge of dead barnacle grey. By now, it has been at least an hour since we first met. Both within and with-of this space in incessant flux, Nino sits directly opposite myself. Light-wall-Nino/Elijah (or is it wall-light-Elijah/Nino?). Though perhaps formed from necessity (I sought him out in the pursuit of understanding), our own relationship pulses. Ebbs and flows, givens and takens or as he might say, “humanity touching humanity – story touching story.” Together, we are becoming something different than before.

Part of Nino’s job at Dying with Dignity is to listen to the stories of individuals struggling with end-of-life decisions. For some, the primary concern is with “me” – loss of the sense of self, loss of the sense of control, fear of the unknown. Indeed, the “dignity talk” (Gandsman and Burnier 2014) of public discourse on physician assisted death often highlights these forms of concern. For Nino, there is little doubt that positive legislation would help to mitigate these concerns. In fact, he believes that without such legislation “there is nothing for [people] to lean into and comfort themselves with by saying ‘okay, there is this law so maybe I want to go with option A or option B.’ Really, since there is no choice you enter a traumatized space where we as a society really do not offer anything to you.” But by offering individuals a “bottle of pills” or some other form of legitimate life-ending assistance, Nino guarantees “they will have dramatically different last days, in terms of internal calmness, than if they didn’t have the bottle.” However, while this assistance may offer an easier way to deal with death, it is unlikely that “this story [of their dying] is somehow going to look nicer.” The factual reality of death will have been dealt with, yes, but “if they want

to do some deep soul searching then drugs will not really help them with that.” Hesitating for a moment, Nino continues, “death is a very charged, emotional event and the way we operate as humans we very easily dislocate the charge that belongs to one story into another story to make ourselves feel better rather than attaching it to where it really belongs.” Though he is quick to point out these individuals seeking simply the factual reality of death cannot be wrong to do so (it is their choice, after all), I wonder how he understands potential legislation as offering an answer to this dislocation of “charged, emotional event.” Where does this charge really belong anyway?

Much like a looped vinyl, a query loosely resembling my primary research question (how does the possibility of an assisted death make dying more meaningful for advocates?) courses through my thoughts. So, maybe because I woke up a bit ornery or perhaps due to Nino’s status as professional working within the movement, I decide to challenge the notion that legislation could do anything other than perpetuate this dislocation. There are days where I understand the argument that physician assisted death is really about facing death, accepting death’s reality, but there are others where I’m confused and wonder if it’s not more of the same “hastening – another way of avoiding death in a sense.” As he patiently listens to this last remark, Nino readjusts and leans forward to be closer as he responds:

It is, but it’s a paradox. So on one level it’s avoiding, but in that avoidance – how that type of avoidance will affect me versus the type that we have now – it’s going to calm me down. As a result, I might have nicer contact with my family and in my environment during the time of my death. And maybe something that would stay close inside of me and unspoken and hidden would come out because I am relaxed [...] So, realistically speaking, the best next step that I see is to offer people whatever legislation is going to offer them. Yes, it’s avoidance for lots of them, but that avoidance will also decrease the trauma and then it will make contact with loved ones more possible and hopefully more stories around death and dying and how that looks like and what’s going on there will hit the surface in the calmer territory than if I’m dying and I just don’t fucking want to see anybody.

This contact with loved ones and growth of stories around death and dying are what is at stake for Nino and many of the other advocates. Yes, the internalizing “my death/dying” trauma remains active for those same advocates, however, many also speak to the importance of pushing beyond this interiority into the trauma marked out on the left behind other. Nino says, “Yes, it starts with me, me, me! I want to pull the trigger, not the doctor – and I deserve that! But then a surprising shift happens once death is there. Their concern drops more into the environment and relationships.” What happens to my loved ones upon my death? Nino reiterates the popular trope of “death denying culture” which makes “it almost look as if we’re not dying.” With death pushed aside and out of view, there’s no surprise that we’re surprised and traumatized when death occurs. The connections of a relationship built over a lifetime abruptly end. Of course, allowing access to a physician assisted death cannot in itself resolve or circumvent the grief and pain left for the still living, but it would hopefully “bring death closer into our society” Nino says. And bringing death closer opens a conversational space where “we agree that you’re going to go. You’re not shocking me in the sense that today you are here and tomorrow you are not.”

Nino emphasizes this point with a story about a former client of his – a successful businessman used to being in control. Having been recently diagnosed with Parkinson’s, this businessman sought Nino’s advice and research on possible methods of deliverance accessible when life no longer became worth living. Without physician assisted suicide in Canada as an option, what could be done? Presumably, upon reaching the stage where he could no longer bear life, he could travel to the Dignitas clinic in Switzerland for a physician assisted death; he could also stay within the Canadian medical system and undergo voluntary stopping of eating and drinking; or, eventually once his body had deteriorated to the point of absolute incapacity, he could

request palliative sedation. After presenting the businessman with his options, the businessman decided instead to proceed in his own way:

Nino: He decided to commit suicide. He jumped into the water because he, through his research, figured out that this is relatively quick, peaceful and no mess. He left his Rolex, his cane, and his shoes on the pier he jumped from so people would know he had jumped. Nobody stole anything. So this *looks* like a fairly, and I don't really want to say non-traumatic, but less traumatic way. He found his way. But listen to this. [pause] After everything, his granddaughter came to see me and said, 'you know, swimming in the water is very different for me right now. And I love to swim.' But no matter where she swims [there's memory]. If he had access to an assisted death [pauses as if to say "who knows"]. So story stays. Unspoken, unfinished stories stay and go on and traumatize the other.

Elijah: [pause] trauma continues.

Nino: Yes! Perhaps assisted dying will still be avoidance, but it's also going to be an opportunity to verbalize some of that stuff [pause] so water can be safe for swimming.

And that's precisely what this chapter is about. The ebbs, flows and pulses of relationship. The connections and barter made through life. The responsibility (or not) that we as a dying person have to the left behind. Or conversely, what the left behind have (or don't) to the dying person. The charge of death and dying belongs somewhere within the relationship between I and Other rather than some other story. When Nino thinks about the end of life, he sees it as a "much more gradual process in which family should be involved. In which things should have been discussed. In which we may even come up with a date together for when I'm going to do it so that the *fabric of connection* (my emphasis) is not wounded in the process." By bringing death back into the picture the water can remain safe for swimming.

Wounded, dead, dying bodies : facts, solvable paradoxes :: 42 : meaning of life

Nino and his fellow advocates of the physician assisted death are not alone in suggesting that our society has misplaced death's charge. The philosopher Robert Solomon observes the ways in which we consistently insulate ourselves against death, that, in our incessant analysis or prognostication of death's meaning and futurity we paradoxically blaze pathways of evasion while maneuvering around death's hold on us. Dying becomes removable from our realities and segmented into series of biomedical stages or philosophical facts. Medical students are initiated in "the insulating practice of dealing with death by not dealing with it, by making it part of routine, by casting themselves always in the role of 'other,' whether hero, helper or mere spectator" (Solomon 1998, 138). Death is that nothing which cannot happen, and yet when it does happen, always happens to an Other. Similarly, echoing Cora Diamond's suggestion that philosophy may not "know how to treat a wounded body as anything but fact" (2008, 59), Solomon claims that philosophers participate in similar insulating practices by turning death "into a paradox and then focusing all of one's attention on resolving the paradox" (1998, 138). In attempts to resolve or clarify the question of death, philosophy often strips away everything that could be considered ancillary – pain, fear, future, others, etc. Static fact, death is made to be nothing more than a limp and toothless ending.

But perhaps some questions, like that of death, "should not be clarified" (ibid., 151). Some questions should remain abstract. Without compromising "our robust sense of personal life and the personal concern about death" (156), it is important to remember the social dimension of death. Stripping away everything that is not the physiologically dead body neglects the reality that humans are "phenomenologically and ontologically as well as biologically, social animals. One's own death is always, except in the most lonely of cases, a disruption (one hopes, not too minor) of

a network of relationships” (ibid.). Perceived in this way, death is constitutive of what Diamond would call a “difficulty of reality” (2008). Borrowing from John Updike, Diamond is concerned with the “experiences in which we take something in reality to be resistant to our thinking it, or possibly to be painful in its inexplicability, difficult in that way, or perhaps awesome and astonishing in its inexplicability” (ibid., 46). Ineffable experience. Something has happened or continues to happen, but resists pinning down – resists the factual and definitive. Philosophy, science and perhaps many of us have an uncanny ability to “deflect” (57) these difficulties of reality. To refuse ourselves the appreciation of these difficulties by focusing instead on the displaced or refracted space of philosophical and moral problem (ibid.). Problems can be solved. The ineffable can only be experienced. Experiencing allows for wounding and presencing. Turning death and dying into defined facts or moments, allows refusal of death’s hold on each of us and instead “[knows] in advance what is at stake” (Stevenson 2014, 31) in any dying. For both Solomon and Diamond then, the questions of death and dying should remain in their abstract and allow for the “being-with/for-others” (Solomon 1998, 156) and serve as “presences that may unseat our reason” (Diamond 2008, 74).

Bureaucratic thought seems to similarly reflect this (f)actualization of death and dying. In her “haunting ethnographic journey” through the mid-century Inuit tuberculosis epidemic and contemporary Inuit youth suicide epidemic, Lisa Stevenson reveals the way in which Canadian policy’s “anonymous forms of care, especially when they tend indifferently to the physical lives of others, can, in a certain sense, be understood as murderous” (2007, 6). In anonymous care, “one cares, but indifferently (7). Throughout *Life Beside Itself*, Stevenson persistently delimits the ways in which it became possible for Canadian bureaucrats to speak of “having” a dead or alive Eskimo and “treating the dead as stately statistics rather than as presences that might unseat our

bureaucratic reason” (33). In their treatment of each Tuberculosis riddled or self-inflicted dead Inuit body as facts to be had, the Canadian state ignores their presences as family members, community members, and friends. They have already been removed from the lived life. In the 1995 Report of the Special Senate Committee on Euthanasia and Assisted Suicide entitled *Of Life and Death*, we are told that committee spoke to more than 150 witnesses concerned with the topic of assisted suicide. A complex set of interrelated factors were considered in coming up with their decision which included the social environment, the family, the dying person, the present state of medical practice, and various health care provisions. And yet, as various individuals actually living their “final stages of dying” whom did not “wish to prolong their illness” (ibid., 70) appeared before the committee, the following question arose: how can “society best *deal* with the suffering of these individuals” (70 [my emphasis])? The suffering-dying subject – what should be done? How should they be allowed to proceed? Perhaps nothing less could be expected from a committee organized to make suggestions on future policy, but what does it really mean to *deal* with the suffering of an individual?

This concern is similarly shared by those in favor of assisted dying. As Leah, a nurse in her mid sixties, and I Skype she reflects on a ten-day hospitalization resulting from a near death experience. And though, as a nurse herself, she understands the time constraints of attending to all of the other patients, she says often felt alone, neglected and burdensome.

You know that [the nurse] is not going to kill you, but she might not give you the support you need. I know because I’ve been on the other side as a Ward nurse years ago [...] you’re just so rushed. You get into [the patients] room and you don’t ask how they are – so what’s being perceived is that I [as a patient] am bothering you. So after a while you begin thinking, ‘Oh she’s coming at that pace and that fast – I don’t matter. She doesn’t have time for me.’ Which is true, but it’s a different context. So [in my experience as a patient] I was able to switch back and forth and realize just how vulnerable the dying person is. Now, throw in a family dynamic where the daughter comes roaring in and suddenly distracts all the dynamics from what’s going in with the person who’s in the dying experience – my god! And then “is the family

just going to stop seeing me if I say ‘would you please shut up?’ It’s my death!’”
And that ability to push back to the family. ... We’ve lost that, the time to sit down
and to be present and just talk about their disease and other stuff with them.

Though buffered from complete abjection by her own experience as a nurse, Leah nonetheless felt the tension and discomfort of anonymous care. Of course, this is not to say that nurses are evil pain mongers, but that the systematic tows of being “just so rushed” can instill a sense apathetic care in which the dying patient becomes a mouth to feed, bed to clean and arm to poke. Shelley, an intake coordinator at a BC hospice and advocate of assisted dying, believes that “dying is a very lonely thing in our culture.” A few days before Shelley and I had spoken she visited a woman who was in her 50s with four kids under the age of 20 and dying from cancer. The weight of this woman’s situation had begun to tire her and as she expressed this to Shelley, her sister refused to hear this and could only repeat “Oh, but you’re going to feel so much better as soon as you work out your will.” But for Shelly, this is precisely the problem. When dying, we are prevented from speaking honestly and having these conversations about how we feel to be dying.

While he considered his position as the parliamentarian “leading the charge on physician assisted death” a bit awkward, former Conservative MP Steven Fletcher saliently understands that “nobody has the [absolute] answer” on how to *deal* with the suffering person. For Steven, the issue of “end of life – of the right to die – [...] goes to the very core of what it means to be human. The core of what it means to be Canadian and what our responsibilities and obligations are to each other as human beings.” Feeling this statement a too bit vague, I ask Steven what he means by this – what is it to be human, to be Canadian, and to be responsible? Without hesitation he draws upon Douglas Adams’ *Hitchhiker’s Guide to the Galaxy* in which Deep Thought, the second most intelligent super computer of all time, tells its inventors that the meaning of life, the universe and

everything is quite simply forty-two. There is no possible way for one to adequately *deal* with the other's suffering. To answer the question of how to *deal* with the other's suffering and dying can only result in the answer 42.

What would it mean then to allow the difficult realities of death and dying to be that presence which unseats our reason rather than a fact to be “dealt” with? To allow dying to be that which can grab hold of us in our fundamentally social dimension? “Seeing a human before you (instead of seeing someone as human) means recognizing their *potential* as company, recognizing them as lovable kinds of beings, capable of showing up regardless of any subject positions they may have been asked to occupy” (Stevenson 2008, 163). Sick or suicidal Inuit. Demented, cancerous, neurologically diseased dying body/patient. These are the subject positions – the attempted shouldering offs of reality. As Shirley, whom we will meet momentarily, reminded me “I know there are two tumors in my head that are cancerous, but beyond that it doesn't look like there is anything else. They're just a couple of centimeters.” Miniscule globby masses which she feared had increasingly begun to define the coordinates of her as positioned subject to the outside world. Dying-stageIV-terminal-colon-cum-brain-cancer-assisted-death-advocate-Shirley.

Memory of Dying

Completely unaware to myself, the Toronto Transit Commission has temporarily closed the Yonge-University Line's subway service between my hotel and Dying with Dignity's Toronto office. Fortunately, their backup plan, an overcrowded, undercooled shuttlebus that stops nearly every block, can get me there in twice the time at no extra charge. Of course, I probably should have left a bit earlier, but I haven't and so I arrive to the “Gentle Conversation” training session stress sweating and ten minutes late. As awkwardly as possible, I burst in and with a somewhat parched throat prattle off a series terse statement/questions, “At least we haven't started! Which

one of you is Margot? I'm the anthropologist from Ottawa." The other eight participants who are sitting all calm, cool and collected while sipping on their free-of-charge Starbucks coffee and presumably becoming acquainted with each other, look up startled and somewhat amused. Right away I can tell that I am quite a bit younger than everyone else in the room. I have a second to wonder how a younger person's presence will effect the conversation before Margot introduces herself and the meeting begins – I guess they've been waiting on me.

There are a few offices jutting off of the somewhat oversized conference room where the nine of us sit for our meeting. The walls are a sterile eggshell white and the lights abrasively fluorescent. It amazes me how colorful a conversation can be in such a negative space. Margot asks each of us for a brief introduction that should include names and reasons for attending. As each of us take our turn, it quickly becomes evident that nearly all of us have experienced the death of at least one friend or family member. After reminding us that this is a training session oriented toward creating meaningful and valuable conversations on death, Margot explains that today has been organized to exhibit positive methods already well used by herself and others like her. And as *Dying with Dignity* is the patron of today's event, Margot tells us that any literature or material used today could be requested for personal use later. With housekeeping accomplished, Margot splays out a number of cards each with its own question surrounding death or dying. These are our conversation starters. John chooses one and asks "How do I want to die?" Jane, "Do I want to be cremated or buried?" Margot, "How much control do I want at the end of life?" Each question spurs conversation, but one sticks out for me. Judy, a journalist and proud Baby Boomer, asks another question: "What about death scares me?" After a brief pause, she answers herself "the idea of my death, how I will die, makes me very anxious."

While the purpose of this chapter is not to trace out how the individual advocates picture their own death, dying or suffering, Judy's response offers a concrete example of how relationship and connection affects our perceptions and decisions regarding death. The deaths of her aunt and mother have influenced her own perspectives and desires in dying. For Judy, and many of the other advocates I spent time with, watching the other's death marks out a space of fear or anxiety toward death. The other's death has scarred her – "[assisted dying advocacy] has been something on the backburner for a long time – at least ten years – mainly because I'm seeing people die very bad deaths." By the age of eleven, Judy had already experienced two of these "bad" deaths – both her mother and her aunt died that year. In a later conversation she elaborates on what she means by "bad" death.

The first bad death was that of my aunt. She had a stroke really early – she couldn't have been any older than 50. She was obese, she was a smoker, and she probably had undiagnosed diabetes, but whatever. She had a stroke and she was terribly paralyzed. They put her together with a nurse who would come in everyday to take care of her, but at night she was alone – absolutely ridiculous! Anyway, she fell again and had another stroke and at that time my mother took it upon herself to bring her into our home and to take care of her. That was just horrific. Years and years – at least three years – she lingered. And she couldn't speak. She couldn't get out of bed, we had to use a bedpan for her, she had to be spoon fed – it was just the worst! That was pretty bad and then she finally died, but it was just awful!

Terrible, ridiculous, horrific, the worst, awful – watching her aunt's dying disturbed Judy. For years she lingered and could do nothing aside from receive food from a spoon. A warm, breathing, digesting body without gumption. In Judy's memory, her aunt could simply do nothing. Regardless of her aunt's perception of her own dying process, for Judy having seen this form of dying as real possibility haunts the future of her own dying. This image of the bad death – the languishing body and all but absent individual – was often juxtaposed against the figure of the good death by the advocates that I spent time with. Regardless of how distant of a memory this death is for Judy, it remains on that backburner – it continues to affect her forward movements.

About half an hour later, Judy works through her mother's death. But rather than honing in on the physical ugliness of dying, Judy remembers her mother's death in terms of its emotional charge. While she has since asked me to keep many of the details unwritten, Judy vividly hashes out the context of her mother's death. A whirlwind of broken dreams and possibly even promises, Judy's story tears into me. She was angry with her mother when she died. She blamed her mother and refused to acknowledge her dying.

I had a lot of guilt around my mother's death. We were not getting along. She and I had a personality clash from the minute that I was born. She was a Scorpio and I was a Leo [laughter]. We definitely had a very fiery relationship. You know, here I was a preteen and I was feeling my oats and I was telling her where to go, and I wouldn't wear the shoes she bought me and all of that kind of stuff. And then she died. I had refused to go see her in the hospital for the last three days of her life because I just didn't want to see her anymore. Talk about guilt, right? Everybody was on my case – 'You should see your mother!' – but I just didn't want to see her anymore.

Perhaps this particular story resonates within me due to my own experience with my mother, but from what I have read and whom I have spoken with, this is a very pressing concern of those within the movement. The guilt of their loved one dying alone or following unresolved and harsh conversations lingers for these individuals. In just the last chapter John expressed his guilt following both of his parent's deaths – 'what if' things had been different he asks. Fortunately for Judy, time and years of therapy have helped to "liberate" her from that guilt, but its scars constructively remain part of Judy's thoughts. Similar to the way in which Judy expresses the memory of her aunt's physical dying, in retelling the experience of her mother's death she expresses the memory of the emotional charge.

Mary Denis, a homecare nurse who spends a lot of time with the imminently dead, is also acutely aware of the traumatic impact a loved one's dying can inflict upon the remaining. As she works through the story of a man in his forties suffering from metastasized melanoma, the details

are haunting. Years of chemo, radiation and extensive surgery had seemingly removed the cancer from his body, but before long it came back with a vengeance – “his spine and femur were crumbling [pause] the pain was just unmanageable.” Admitted to a nearby hospice center, this man spent days, weeks and months living in “pain that was completely out of control.” Deciding not to undergo palliative sedation³, the lengthy and beleaguered dying process profoundly affected his wife. Mary says that “his wife is still really suffering with PTSD after having witnessed this dreadful, prolonged death. He’s long gone and she’s suffering still. Nightmares and terrors.” Mary has suggested she seek out a physician’s referral to psychologist or psychiatrist as the death that she witnessed was no “ordinary death” and normal hospice grief counselling would not help. Not an ordinary, but extraordinary death – one powerful enough to leave the wife with nightmares and terrors. Of course the husband’s decision to remain alive could only ever be his own – Mary is not advocating a forced sedation – but what is important to realize here is the extent of the impact.

In light of these three brief, yet powerful, examples an entire continuity of memory becomes visible. While, as we have explored in the first section of this chapter, the acknowledgement of death, dying and suffering’s real hold on each of us is often deflected, the resultant memory of the process continues to grip long past the event itself. It has been over 40 years since Judy’s aunt and mother died, but the memories continue to affect her thoughts. What a convoluted paradox. On the one hand, death is adamantly, though often unrecognizably, pushed away. On the other, and it is important to understand the timeline here, once death has occurred grievous effect is easily recognized. This is common even outside of the advocates that I spent time with. Take a walk around the aisles of the local bookstore and you are likely to encounter several books offering some sort of advice or companionship as you work your way through death’s aftermath. I myself

³ Mary wonders aloud why he decided not to undergo palliative sedation. Was it because “he was already a bit confused with his illness? Was he metabolically unbalanced? Was his thinking process clear?”

read C.S. Lewis' *A Grief Observed* in which he confronts the immeasurable grief of his wife's death. Spiritually tinted toward the Christian, Lewis draws on God's love and beauty to work through his pain. Similarly, poet Christopher Reid offers up a eulogy of sorts for his late wife in his collection *A Scattering*. Sorrowfully tracing out the ways in which his wife's death has left him alone with "Memories. Weighty emptinesses" (2009, 61), Reid admits that he often passes by the research institution where his "dead wife lives now" (49) or visits an Italian market to remember his dead wife's "feminine element his life has lacked for too long" (48). Each of Reid's steps remind him of the way in which his wife is dead and will never again greet him along the stairwell or come home late from work to slip in bed beside him. Invoking the image of elephants ritualistically scattering the bones of their dead, Reid asks their spirit to "guide me as I place my own sad thoughts in new, hopeful arrangements" (38). Judy's years of therapy, Lewis' faith in God, Reid's call to elephants – attempts to address death's continuity in life.

Three weeks

Let's return to my time with dying-stageIV-terminal-colon-cum-brain-cancer-assisted-death-advocate-Shirley. I am sitting on a poorly padded brown stump of a box surrounded by hordes of unwashed clothes begging for attention. The laptop sits about a two feet away balanced precariously on a couple of old history books resting cockeyed on the only relatively clear surface in the room – the corner of my bed. As I test the camera and microphone, I am careful to place myself square and center screen so Shirley cannot see the sprawl beneath and beside. She and I have yet to meet in person. A friend of mine, John, introduced us a few weeks back via electronic courier. We've exchanged a few emails since, but most have dealt specifically with the details of our imminent Skype session. In his email, John explained my work as a "review of people's

response to the possibility of dying” and mentioned that I “was hoping to locate someone who was much closer to facing this reality than I [John] appear to be at this time.” Though I had indeed expressed this desire some time before, I was shocked by the audacity of those tiny black words. It was the first time I had really seen my desire to be closer to death so brusquely written. I feel very small as our conversation begins.

Back on my stump, our technologically mediated encounter confuses perception. Without a built-in camera on her computer, Shirley places me on the desk about a foot below the right side of her face. While I’m pretty sure my corporeal remains the same size as before, the entire encounter reminds me of the 80s Disney movie “Honey, I Shrunk the Kids.” Compounding the absurdity of my own virtual positioning, Shirley looks directly ahead – presumably at my full-sized figure on her own screen. Again, while I’m almost certain that I play an integral part in the conversation, there is a fair chance that I am just a spy. Then the sensation of cracked lips and dry tongue plodding around some verbal arrangement draw me into the conversation. The voice emanating from my side of the screen asks something along the lines of “where do you find yourself as fitting within the right to die movement?” Though this question typically allows the inquisitor to remain distanced and disconnected from the interviewee, Shirley’s reality will not be shouldered off. “My husband and I have talked about it a lot. I’ve been given a twelve month prognosis, but of course that’s just an average, right?” What? I already knew this fact, but somehow these words place their hands on my cheeks, peel my eyes open and stare into the abyss. Reading them on her blog and then hearing them in her unquivering, even jovial, voice cannot compare. And to add the tag “but of course that’s just an average, right?” – what sort of person am I talking to that could make the potential one year left of living sound so terrifyingly blasé? With the

prognosis still clanging around my tympanum, my oral collective blurts out the only possible response: “Right, but when did they give you this? I must have missed that on your blog.”

Something is wrong here. Visual and emotional points of view are askew. Part spy, part researcher, part Elijah, part tons-of-other-things I shouldn’t be *feeling* yet. The opportunity to soak in the objectified-façade of dying-stageIV-terminal-colon-cum-brain-cancer-assisted-death-advocate-Shirley has not been granted. The clear lines and contours of the object-researcher relationship have already begun to smudge. Releasing their contents, Shirley and Elijah begin to seep together – Shirley-Elijah. Sure the speed of our movements toward each other must forever remain slower than those movements connecting us to other individuals more commonly a part of our lives, but I am nonetheless overwhelmed by our mingling. As I have already called attention to with the introduction of this chapter, relationship, connection and togetherness are vitally important for both the currently healthy and the dying of the assisted dying movement. Much like my time with Shirley, the broken boundaries and slow seepages of my interactions with many of the other advocates easily attests to this importance of the Other. But I, by no means, am the most important Other for any of them. Shirley’s husband and son are certainly of more import than the spectator-researcher that I represent.

In April, just a couple months before our conversation, Shirley’s neurologist had given her the twelve-month prognosis. As I have already shown, she points out the contestability of this number. However, this is not a deflection as Stevenson or Diamond might say. She acknowledges the very real potential that at some point she will decline. Decline and then die. This decline, while extremely difficult for herself, will only be more so for those surrounding her. “I worry about the impact [my death] will have on them. I think about how I can lessen that impact in some way and I come to the conclusion that there’s not much that I can really do about it.” Without the power to

change the situation, Shirley falls on how our friend John (among others) talks about controlling “how you respond” to the situation. Dying’s outcome is inevitable – there will be some sort of residual pain remaining with the other.

Shirley: When you die you die. I don’t know if dad and I talked about this, but it’s easier for the person dying than it is for the people who will remain because I have an ending. I know that at a certain point I’m done. But everyone around me has the aftermath to deal with when I’m no longer here. So, for me, in some ways it’s easier. Like I know with my dad, I remember thinking once he passes, I have to deal with him no longer being here, but he doesn’t. You’re gone! I will be gone, but my husband, son and friends will have to deal with me not being here and that void or emptiness.

Elijah: Do you think then that we have a responsibility to die in a certain way? A responsibility to make this void, this aftermath, less difficult for other people?

Shirley: Honestly, I’ve been thinking about that a lot. If you have the chance, I think you should. So one thing that I’ve been doing is writing letters. So, you know a week or month after I die, they can open them. When my son gets married, there’s a letter. If he has a child, there’s a letter to read. I haven’t finished them because they’re hard to write, but there’s something left. I’m sort of there.

Elijah: That’s beautiful, Shirley. And as we’re dying? Do we have a responsibility?

Shirley: So, I think when I’m with my husband or friends, I always try to end with an “I love you” or something like that so that if it is the last conversation, and I’ve actually said to my husband and son through this, “Let’s be kind. We need to be kind to one another. Not that it will be easy, but let’s try and focus on being kind and what is good here. Not focus on what’s coming.” It’s easy to get caught up in the future and the potential nastiness that’s coming, but let’s focus on the good that is here right now.

There’s something left. Shirley remains. She continues. I doubt this comes from a place wholly concerned with not being forgotten, though that certainly comes into play, but more from a desire to continue to be something held by her child and husband. The time of kindness remains. Perhaps this is not an example that perfectly exemplifies how accessing a pill will circumvent this pain, but she does present a beautiful example demonstrating the interconnectivity that those within the movement realize. Actually attaining the assisted death is only one, dare I say minor,

concern for many of these individuals. More importantly, there is a sense of connection to those left behind and a desire to leave them with positive memories. Later on she seems to clarify this point when she says “My husband and I have had deep conversations about what I bring for him and how he’ll cope when I’m gone. That’s a deep conversation! [...] And I often talk with friends about the lastingness of our friendship. Acknowledging the importance of the other person and my role in their life. I guess that’s more the subtext of the conversation. The importance of the relationship between the two.”

Within three weeks of our conversation Shirley was dead. The plans she and her husband had made for their final weeklong getaway would not happen. Her son would not feel her embrace at his eventual wedding. Her grandchildren would never know her. And though I cannot help but hurt for her husband and son, I sense that Shirley is still with them.

Holding

(F)actualizing the suffering, death and dying of these individuals by questioning how to “deal” with them refuses to recognize their hold on our lives. Sue was in her early forties and had been living in Ottawa quite a while by the time her father was diagnosed with both Parkinson’s and Alzheimer’s. For years she had not seen her parents more than the three or four annual trips to Hamilton would allow, but as Parkinson’s and Alzheimer’s quickly learned how to control her father’s body her mother was forced to seek out help. Eventually settling on an apartment a few blocks over, her parents’ move to Ottawa was a life changing (though not wholly unwelcome) event for Sue. Somewhere in her teenage years, Sue says that her father “checked out emotionally. And I’m going ‘Dad, dad! What did I do wrong? How come you don’t love me anymore? What, what, what? If I’m better at school? If I’m prettier – if I do more?’” For years their relationship remained strained and “fraught with fear.” Unsure of why she was so afraid, she would ask her

sister if he had abused her or shamed her in some way – “how come I’m so afraid with dad?” While in some way she knew that “he always loved me – he always loved me totally,” the emotional distance created over thirty years seemed insurmountable. And then, in the midst of his sickness, an important event occurred. He asked for help to take a shower. “The whole family disappeared! They evaporated! And I was going, ‘Okay dad, I’ll help you with a shower.’ [pause] So I get in the shower, I bathe my dad, [pause] and something happened in that. I think something happens when there’s a physical closeness. Something shifted for dad and I, and I felt his love totally. And my relationship with my dad changed totally after that.”

Of course the legacy from thirty years of “why don’t you love me anymore” remained, but somehow this physical closeness with her father’s ailing body began to break down the barriers between the two. She visited him more often, massaged his feet, helped him bathe - whatever he needed, she was there to help. This intimacy of bodies forced upon her the difficult reality of physical disintegration and mental deterioration. As active participant in her father’s dying, questions concerning “death and dying and the implications of dementia” certainly weigh heavily on Sue’s thoughts. Like Judy and her mother’s death, Sue’s experience with her father has partially influenced her support of assisted dying. Unlike Judy, however, this support has not arisen from a wholly negative position. Whereas Judy feels the burden of guilt over not having had the presence of mind to visit her mother and seek out that relationship as she was dying, Sue’s is found somewhere within the painful memories of these physical moments. Both a physically and emotionally holding his death.

The Exceptional Death

Opening his essay on voluntary death among the Chukchi, an indigenous group living in present day Russia, by questioning what is at stake in this death, Danish anthropologists Rane

Willerslev resists the temptation of the simple exoticisation propagated by several accounts before. Refusing to reduce the voluntary death to the simple result of environmental or technological conditions, Willerslev meticulously traces out the ways in which voluntary death emerges as prime example of the optimal sacrifice. As nomadic reindeer herders in the remote Siberian north, some anthropologists have argued that the voluntary death reflects little more than death from necessity (i.e. the elderly become too much to take care of due to decreased mobility, ill health, etc.). However, for Willerslev “If what is at stake in voluntary death is simply an old and sick person giving up his or her life because of feelings of uselessness, then that person could presumably put an end to his or her own existence instead of asking others to do the killing – and in a ritualistic fashion, at that” (2009, 694). So again, we are confronted with the question – what is at stake?

In the Chukchi cosmos, everything that exists in the world of the living pairs “with almost endless doubles of itself, which extend in all directions and continually reflect and echo one another” (ibid., 695). As prime exemplar of this hall of mirrors, the loosely connected worlds of the living and the dead reflect upon each other albeit with a peculiar twist. When staring into the world of the dead, the living would notice that while their deceased ancestors live in nearly identical skin tents with family and herd reindeer much like themselves, their bodies are turned inside out, their heads and feet bend backward and time flows much differently than our forward-running time on this earth (696). Similarly, when the dead stare back into the world of the living, time, shape and action seem somewhat familiar though tinged with some sense of difference. Compounding the dissonance between these outwardly experienced differences, Willerslev notes that both worlds’ residents consider themselves equally alive and the other equally dead. The Chukchi ancestors welcome the souls of the recently departed as the “physical return of a long deceased relative” (ibid.). Likewise, an Earthen birth constitutes a return – “the child is given the

name of a deceased relative and actually assumes, at least formally, that person's place within the wider network of kin" (ibid.). Death, then, plays a necessary part of the "creative circle of renewal" (ibid.). However, the exchange of soul stuff between the two realms is hardly equivalent as the ancestral are afforded a permanently superior status and "hold ultimate authority over life-giving souls" (ibid.). Though each Chukchi may currently possess their own soul and reindeer, both ultimately belong to the dead. Thus, at any point, the deceased may invade this world and take repossession of what is rightfully theirs.

As a defense against this invasion, Chukchi give partially self-sacrificial offerings to their ancestors. Reindeer, fish, sausage and more represent parts of the individual and serve as substitutes of self in the hopes of appeasing the desires of the dead. Desires met, the dead will not wreak havoc on the living. Thus, while these sacrifices all range in levels of importance, all seem to have the common denominator of the "maintenance and furthering of life through the act of taking life" (Mack 1987:3; seen in Willerslev 2009, 701). Life can continue because the dead have been pleased and no longer want to repossess what should be theirs. However, all Chukchi also know that what the ancestors truly yearn is the human soul – the return of their (perceived) dead relative. Only the human can serve as the optimal sacrifice. And as with all other sacrifices, the human must willingly be killed rather than simply chosen and murdered. It is with this understanding that in times of extreme turmoil, after all else fails, the human steps forward and presents himself to the still living family as the sacrifice that must be offered. All other sacrifice can only be inferior. The voluntary self-sacrifice, then, provides "an occasion for reflection on the fact that what ought to be killed is not usually killed but is exceptional" (Willerslev 2009,702).

While exact comparison between the Chukchi and Canadian assisted death advocates would be trite, something about this last sentence powerfully resonates with Nino's "fabric of

connection.” Solomon (1998), Diamond (2008) and Stevenson (2012) speak to the ways in which death becomes deflected in philosophical, biomedical, political and moral thought. Death refuses “dealing with” or “thinking through.” Rather death requires experiencing by “being-with/for-others” (Solomon 1998, 156) as one of those “presences that may unseat [our] reason” (Diamond 2008, 74). A difficult reality to be sure, but in our attempts to evade this reality by moralizing, postponing or othering, it would seem as though “what ought to die does not usually die but is exceptional.” Death surprises us. Or rather, as Nino says, we tend to live “almost as if we’re not dying.” Perhaps some would contend that the technical aspects of the assisted death place advocates within the same realm of evasion (Lavi 2007), but throughout this chapter I have attempted to explore what is at stake for the advocate. If death is all that is at stake, then as Nino says “VSED [voluntary stopping of eating and drinking] is going to shorten your trouble in the frame of 14 days instead of 2 years. And you’re saying that nothing is available to you?” Death itself is always available, but what seems to be truly at stake for the advocates speaking here is that fabric of connection. Sitting with the reality that death is literally a pill away, brings death back into life. Connection, relationship, presence. In a world inundated with the possibility of never dying and the pressure of postponing death, advocates are attempting to bring death back. To make life meaningful in relation to death.

Conclusion

The explanation is obvious. *The Garden of Forking Paths* is a picture, incomplete yet not false, of the universe such as Ts'ui Pên conceived it to be. Differing from Newton and Schopenhauer, your ancestor did not think of time as absolute and uniform. He believed in an infinite series of times, in a dizzily growing, ever spreading network of diverging, converging and parallel times. This web of time – the strands of which approach one another bifurcate, intersect or ignore each other through the centuries – embraces every possibility. We do not exist in most of them. In some you exist and not I, while in others I do, and you do not, and in yet others both of us exist. In this one, in which chance has favored me, you have come to my gate. In another, you, crossing the garden have found me dead. In yet another, I say these very same words, but am an error, a phantom.

(Borges 1962, 100)

When I first began my research, I will admit that I had not expected such an overwhelming focus on spiritual transformation or the importance of relationship at the end of life. When I asked the question of how advocates believe assisted dying to create a more positive space for death and dying, it was assumed that something about wanting to say goodbye to everyone would be entertained. My own experiences with my mother's death made it to where assisted dying seemed attractive in the sense that I would be more aware of the actions and emotional responses if assisted dying were legalized. What has been surprising, however, is the way in which for many of the individuals that I have spent time with, the death part of assisted dying was only a peripheral concern. More importantly for several were the continuation of relationship and creation of one's self toward the end of life. That assisted dying is legalized and available makes it easier to focus on these other important aspects of dying. Entertaining the thought of assisted dying as a form of spiritual asceticism. Allowing oneself to die as a way of showing to others that "what ought to die does not usually die but is exceptional."

Reflecting on the Russian writer Nikolai Leskov, Walter Benjamin (1968) suggests that we have lost our ability to share stories – to share experiences. Storytellers, like Leskov, though familiar figures in society appear as something "remote from us and something that is getting even

more distant” (ibid., 83). The reason? At least one, he suggests is that “experience has fallen in value” (84). Experience no longer connects anything. Rather, Benjamin writes we receive, the daily news every morning which is “already shot through with explanation. In other words, by now almost nothing that happens benefits storytelling; almost everything benefits information. Actually it is half the art of storytelling to keep a story free from explanations as one reproduces it” (89). Stories are still written, but in many cases what they are supposed to mean or how they are supposed to end are already given. For Benjamin, this is a failure of storytelling.

Death is another such storyteller. But with wellness and the related avoidance of disease, illness and dying being seen as a contemporary “path to salvation” (Lock and Nguyen 2010, 28), death’s ability to impart some counsel on the lives of the living has slowly receded. For many, their advocacy for assisted dying is an attempt to reinvigorate the idea that death and dying must be seen as a story continually unfolding. Some, like Shirley take extreme measures to make the connection between death and life, for their family members. Her decision to write a series of letters for her husband and son to read at various times following her death, allows her to remain a present and active story in their life long after her death. Others, I am thinking of Nino and Sue, would allow the death tell its own story. Taking his cue from Steven Jenkinson, Nino simply offers that “death has something to teach us.” When I pressed him to clarify, he could not.

As Benjamin continues to work out his contrast between story and information, he juxtaposes the storyteller to the novelist. The storyteller can remain unfinished. The storyteller can allow the story to escape at all the edges. The “novelist, on the other hand, cannot hope to take the smallest step beyond that limit at which he invites the reader to a divinatory realization of the meaning of life by writing ‘Finis’” (100). It has increasingly become my understanding that many of my advocate friends are attempting to bring story back to life. The novelist, the memoir, and

the biomedically mediated death – these forms bring about a summation, a final meaning. It is only once someone has died that their lives, knowledge and wisdom are able to be recounted. Life, for my advocates, does not seem to work this way. Story is a thread that continues to work its own way throughout our lives. Story can never be finished. Story can only pause. When the advocates I spent time with talk about wanting to leave behind something better, they want to leave behind a better memory from which new stories can spring. Advocates are not seeking the finis of the actual death. Rather they are seeking to weave a positive story of death back within society.

Tim Ingold introduces his collection of essays entitled *Being Alive*, by positioning anthropology as a sustained inquiry into the potentials of human life. For generations, he says, anthropological theorists have all but cut the life out of their accounts preferring rather to factualize their objects of study. For example, he draws upon Geertz who has written that human life is that which begins “with the natural equipment to live a thousand kinds of life,” but is expected to “end in the end having lived only one” (1973, 45). From this perspective, life is nothing more than movement toward “terminal closure: a gradual filling up of capacities and shutting down of possibilities” (Ingold 2011, 3). Rather, Ingold proposes a conceptualization of life as that which is capable of repeatedly negotiating and passing such closures. “It is of the essence of life that it does not begin here or end there, or connect a point of origin with a final destination, but rather that it keeps on going, finding a way through the myriad of things that form, persist and break up in its currents. Life, in short, is a movement of opening, not of closure” (ibid., 4).

As an issue currently at the forefront of interdisciplinary debate, assisted dying is a conversation about the “good” death. Dying with dignity – dying meaningfully. That being said, it has come to be my understanding that while many advocates do have an idea of what a good death might entail, there is a hesitancy to pin down a singular definition. Now that assisted dying

has been legalized in Canada, parliament and bioethicists are attempting to work out who will have access to the assisted death and the moment at which this becomes a possible option. And these are important debates as otherwise an anarchic system of disregard for human life may indeed become a reality. But what this attempt to pin down fails to understand is the way in which though the aim may be for the good or meaningful death, many advocates have no resolute idea of what makes this death. Yes, several individuals state that once the pain becomes too great then I may desire this death, but as our chapter on spirituality demonstrates, Karen and Sue found it difficult to decide ahead of time when it might be the right time to access an assisted death. Though both have seen several deaths that they undoubtedly place in the category of “bad” determining what is good or meaningful is much more difficult to discern.

Rather than attempting to define just what the good death is or is not, some advocates perceive the end of life as time for spiritual transformation. Nino described this by referencing a tale from the Knights of the Round Table – the Chair of Transformation. Accessing the assisted death on its own, though certainly helpful, cannot create a meaningful death. Meaning and the truly good death can only be found by working on oneself and being willing to transform oneself throughout the dying process. Knowing that there is always the option to die sooner if this work of transforming becomes too difficult allows for a more focused effort on this transformation.

Throughout the course of this thesis, I have been welcomed into thoughts, deeds and experiences of several advocates of assisted dying, and it has become clear to me that many of them promote similar reflections on life. In my time with John, he invited me to reflect on living within a different mode of time. John calls me to consider the “what ifs” of life, living and dying. What if he had helped his mother die or told his father not to hang on, but to welcome death? What

if life itself weren't seen as absolute value in and of itself. What if life were bracketed off from living? What would it be to live in such a way?

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