7. Escaping Biosecurity? The Question of Security in Dying and the Possibility of Doing it Otherwise

> In this world, nothing can be said to be certain, except death and taxes.
> *Benjamin Franklin*[1]

Certainty in the sense of knowing (one's risks) has been a crucial element in the biosecurity narratives discussed in the previous chapters. However, the certainty of death as expressed in Benjamin Franklin's words in the epigraph represents a qualitatively different kind of certainty. Though death epitomizes the one certainty in every life, it does not coincide with the understanding of biosecurity outlined before. Rather, it represents the antagonist in the dominant biosecurity narrative of controllability and survival. The previous chapters have shown how logics of biosecurity are applied to non-contagious disease contexts, permeating the understanding of health and heavily influencing individual identity constructs. The biosecurity narrative discussed up to now relies on the promise of survival and the prolongation of life, and more specifically and systematically the controllability of the body. The analyzed security narratives show that these security practices which promise control and manageability represent the main stakes in the gospel of biosecurity. But what happens when this promise ultimately fails? In this chapter I will turn to the moment when the biosecurity narrative of survival, good life and control fails, namely during the process of dying.

Though death and dying seem to represent the ultimate failure of the messianic narrative of medical salvation, security narratives play an important role in the understanding and experience of this last biological process of life. And while unquestionably a biological process death cannot be regarded as neutral, rather it is almost compulsively judged and evaluated as good or bad depending on the understanding of security. Today, a good death is largely perceived as a quick and painless death at the end of a long (and

1 This quote is often attributed to Benjamin Franklin. However, it exist many different versions attributed to different people, including in Christopher Bullock's *The Cobbler of Preston* from 1716: "Tis impossible to be sure of any thing but Death and Taxes."

ideally fulfilled) life.[2] But even more important than how long life lasted is the absence of prolonged physical and mental debilitation before death finally occurs. The evaluation of death is thus bound by the temporal period preceding it and is determined by the process of dying. It is rather a question of dying well or badly which defines security in death. Therefore it is imperative to analyze the *process of dying* rather than *death* as the mere end point.

In dying the original biosecurity promise of "survival" and "good life" is substituted and replace by the security of dying well – of dying with dignity as it is called today. What that means exactly, however, has changed throughout history. Today, competing narratives of dying well reveal the failure of the promise of biosecurity and their security practices.[3] The security narrative promising to die well with physician-assisted dying (PAD), which is the focus of this chapter, represents one of the counternarratives to biosecurity and an escape from its prescribed security practices. I will argue that the narrative provides a revision or reinterpretation of what security in dying, or "dying well" means and what threatens its success. By discussing PAD as security practice I wish to focus on the turning point of the security narrative: the moment when a new promise is replacing the old.

The documentary *How to Die in Oregon* provides one of these narrative efforts and will serve as an example for the construction of a security narrative in and of dying. With the documentary I will turn to a further discursive formation, one that is both visual and auditory. Similar to the life writing genre discussed in the previous chapters, documentary filmmaking has its own implications regarding authenticity. Life writing texts and their supposed adherence to mimesis still create the appearance of truth and "veracity" based on the "autobiographic pact" (Lejeune 3–30), though they are widely acknowledged for their inherently "fictional" characteristic: the creation of a "truth" and a life through the telling of the story. Likewise, images (both photography and documentary) are commonly bestowed with a similar authenticity perceived as a mimetic representation of a reality. The director Peter Richardson uses this claim to authenticity in his construction of a pervasive narrative representing self-administered death as a valid and necessary security practice. As a full length documentary dedicated to the right to end one's own life, *How to Die in Oregon* is rather unique and was crucial in the debate and circulation of the security narrative of dying well in the United States.[4] The construction of the secu-

2 Clive Seale asserts that "[i]n the Anglophone world, confessional deaths in which terminally ill people fight, face, and eventually accept their deaths, reconciling themselves with their loved ones, retelling and sometimes reconstructing personal biographies, presiding over their last days" ("Media Constructions" 967) is represented as a good death. For a more detailed exploration of dying well today see T. Walter *The Revival of Death* (1994), or Susan Orpett Long "Cultural Scripts for a Good Death in Japan and the United States: Similarities and Differences."

3 Lydia Dugdale demands in "The Art of Dying Well" that it is the responsibility of bioethics to rewrite a directive for dying well (a modern *Ars Moriendi*). Others argue for a more spiritual approach (Ayeh, Derek), Nursing Studies are often calling for life writing conduct to create heroic life narratives (Seale and van der Geest "Good and Bad Death").

4 It was such an important representative milestone that the documentary is featured in the short history of aid in dying on the *Compassion and Choice Homepage* alongside the history of legislative changes and groundbreaking cases such as Terry Schiavo's.

rity narrative supporting the practice of assisted dying in this documentary is therefore paradigmatic for the necessity of narrative in creating a pervasive understanding of what security in dying means. I will first interrogate the cultural history of dying well to then turn to the security narrative that juxtaposes the "beautiful death" with the loss of dignity in dying. I will question if this challenge to the normative biosecurity narrative of surviving can represent an escape from the normative power of biosecurity. I aim to argue that the narrative construction of security in dying relies on a normative understanding of the able body and "the human," and is established in relationality to the other.

Dying Well and in Time: A Shifting Narrative of Security

Security narratives almost never emerge out of nowhere, as the previous chapters have shown. They relate and refer to previous versions of security, representing alterations or re-interpretations of older narratives rather than entirely new ideas or concepts. Also, the understanding of attaining security in death and dying – so the security practices in dying – have repeatedly shifted throughout history, depending on the changing narratives constructed by different narrative perspectives and voices. According to the historian Philippe Ariès, who has published extensively on the history of Western attitudes toward death and dying, the practices surrounding these changed very little over long periods of time.[5] The 20th century, however, has been marked by faster and more radical changes than before: "In our day, in approximately a third of a century, we have witnessed a brutal revolution in traditional ideas and feelings. . . . Death, so omnipresent in the past that it was familiar, would be effaced, it would disappear. It would become shameful and forbidden" (Ariès, *Western Attitudes* 85). This "brutal revolution" was facilitated by changed living conditions and cultural changes, but most crucially it was driven by the increasing medicalization of life which went hand in hand with changed practices in death and dying. In fact, not only the attitudes and perceptions have changed, but the process of dying itself has been altered by the all-encompassing reach of biosecurity.

For the longest time – the seminal text on the attitudes toward death by Ariès spans over "the last one thousand years" (*Hour of Our Death*) – death and dying were religiously determined practices governed by the Church. In the Christian context the security practices were derived from the Catholic *Ars Moriendi*, a Middle Ages text elaborating rituals that were supposed to guide and console both the dying and the bereaved.[6] Ideally, dying was a time of preparation that took place in one's home surrounded by family and friends and with the guidance of a priest who administered the last rites. This tradition of the deathbed represented a security practice that made the process of dying a necessary conclusion of a life and gave meaning to the suffering in dying. This last act can

5 In this chapter I will exclusively refer to Western ideas and conventions of dying. Every culture has its own very complex understandings and rituals concerning death and dying. The processes in different cultural contexts can thus not be conflated to one biological process that every person experiences at the end of life.

6 Similarly to the Christian A*rs Moriendi*, in Tibetan culture the *Bardo Thodol* is another example of such a security narrative.

be structurally compared to a performance in which all participants enacted prescribed roles following a common script that described the process of dying (securely). The process of dying, thus, consisted of highly ritualized practices that were largely "organized by the dying person himself, who presided over it [the ritual of dying] and knew its protocol" (Ariès, *Western Attitudes* 11). This means that the dying individual had an active role in the deathbed rituals: resolving remaining affairs, distributing responsibilities as well as possessions and speaking the last farewells (Ariès, *Hour of Our Death* 448). The knowledge of one's nearing end – the awareness of death – was therefore crucial to facilitate the rituals of the deathbed, which represented security practices that prepared for a good death.

Furthermore, dying was a public event that stressed the importance of awareness and of acceptance as the prerequisite for a good death. Though not always necessarily welcomed initially, death was to be accepted as the divine act summarized in the Christian tradition with the biblical citation "the Lord gave, and the Lord hath taken away" (King James Bible, Job 1.21). Accordingly, the individual was expected to die in peace, humbly receiving their handed fate. Since the time of the deathbed was regarded as highly important the solitary and unexpected death was feared. It did not provide the opportunity to resolve earthly matters, confess sins, and receive the sacraments and therefore represented a great threat at the end of life. The acceptance of death at the time determined by God also meant that the intentional death – suicide – was condemned, as life was only to be taken by God. It was understood as a violation and an unforgiveable sin, which was sanctioned with the exclusion from security in the beyond and was symbolically often marked on earth by a burial place outside of the boundaries of the graveyard, as it represented a bad and shameful death (Kellehear, *Social History* 86).[7]

With the normative power over the process of dying shifting from religion and priests to medicine and doctors the cultural rituals, such as the gathering at the deathbed, were challenged and changed by new security narratives that rendered the former practices a threat. During the first half of the 20th century dying turned from a ritualized public practice into a hidden and denied part of existence. The new arbiter of security promised the controllability of the body, and highlighted the potential possibility of cure, which raised new expectations of security. The process of dying, however, made visible the deceptiveness of this security promise. Dying, therefore, became more and more closely associated with loss caused by a failure of medicine and the individual alike (Ariès, *Hour of Our Death* 586). Individuals were blamed for diseases supposedly caused by irresponsible behavior: drinking, smoking, unhealthy diet, not enough exercise, too few preventive medical exams, the list is inexhaustible.[8] The loss against "nature" was no longer regarded as a "natural" end but as a loss caused by the misconduct of the individual and the shortcomings of medicine.

7 This stigma attached to suicide still exists in a secularized form as moral judgment, ranging from pathologization to the judgment of simple cowardice.

8 The blame for disease is not a new phenomenon but prevails in the long history of the cultural construction of disease. For a detailed study see Ariane Schröder *Biological Inf(l)ections of the American Dream*.

Furthermore, the new arbiter of security and the new security practices converted the dying into the sick as "death has been replaced by illness" (Ariès, "Reversal" 140). Dying well now meant to deny it, or rather to refuse to die and to fight for life until the very end. In a way, it meant not dying at all, but rather transitioning directly from being sick to death.[9] Various studies and reports emphasize the dilemma for medical practice which is "adept at sustaining life" (Dugdale 22) but not at letting people die, let alone helping them to hasten the process.[10] Accepting death and "giving in" became therefore perceived as diametrically opposed to the normative security narrative established by biomedicine, which is based on fighting and survival, as discussed previously.

The representations of death and dying became increasingly dominated by fear, sorrow, and threat. With the growing influence of medicine and the waning power of the Church, suffering in dying became a meaningless experience within the scientific framework that defined the new security practices. With this shift, the experience of dying was altered from a familiar to an abject event, and death was increasingly perceived as a "nauseating spectacle" (Ariès, *Hour of Our Death* 569).[11] The changed attitude went hand in hand with the change of practices in dying and ultimately the displacement of the space of dying. The public practice of the deathbed became first a private gathering of the closest family and friends, who had the moral obligation to bear the sight of the suffering in dying and whose presence would not humiliate the dying individual. In a changed form the deathbed gathering was still practiced until the 1930s, while most other accompanying traditions were lost. The home as the setting for the deathbed – the iconic space of security – was in the following two decades increasingly replaced by the hospital. There, medical professionals were able to administer necessary treatment to maybe save the life (one more time) and avert death. The hospital represented the new security practices in dying, and the new symbolic space of security. However, since people were rushed off to hospital, death and dying seemed to have disappeared from the public sphere. The changed security narrative which stressed survival and the utopian idea of the controllability of the body had not, of course, eradicated dying but had made it "invisible."

The deathbed gathering was ultimately abandoned in the middle of the 20th century, because the presence at someone's dying was perceived as increasingly uncomfortable

9 Marelli and Moses point out in their analysis that modern obituaries often include the cause of death and explicitly state "after (long) illness" (129).

10 Lydia Dugdale, among many others reports in the Hastings Center Report 2010 about how individuals are kept alive, such as the "elderly woman with end-stage dementia readmitted to the hospital for the fourth time in three months for anorexia, now with a feeding tube" (22).

11 The increasingly widespread use of sedatives was also progressively better able to control and alleviate the pain in dying. At the same time, these medications also decreased the visible, or rather audible, suffering of the patients, which represented alleviation also for the "audience" of the deathbed scene. Similarly, post-mortem rituals reflect the important role of the survivor in determining the understanding of security in dying as Elizabeth Klaver asserts. Embalming has been an established practice in the U.S. since the Civil War. It primarily preserves the corpse but it also eradicates the traces of suffering as visible signs of dying. Jessica Mitford shows in *The American Way of Death Revisited* that the funeral industry in the U.S. has used this argument of "therapeutic" benefit for the bereaved to legitimize the excessive and expensive post-mortem procedures. The signs of incontrollable suffering are erased by the mask of security that fits more neatly the biosecurity fiction of controllability.

and intolerable for those witnessing it. Furthermore, the knowledge that one was dying was deemed unbearable for the afflicted individual. The biosecurity promise that life could be controlled and disease cured became so strong that the knowledge of a fatal condition was perceived as an insurmountable burden for the afflicted person. The dying were therefore often not informed about their fatal condition. Ariès explains that, "it was unquestionably clear that the primary duty of family and doctors is to conceal the seriousness of his [their] condition from the person who died" (Ariès, "Reversal" 138).[12] This "new" security practice represents the reversal of the understanding of security in dying that stressed anticipation, consciousness, and acceptance as core elements of a good death. Awareness in and of dying, which represents one of the cornerstones of the security narrative that promised a good death up to the beginning of the 20th century, was reinterpreted as a threat. "What today we call the good death, the beautiful death, corresponds exactly to what used to be the accursed death: the *mors repentina et improvisa*, the death that gives no warning" (Ariès, *Hour of Our Death* 587). Awareness of immanent death was perceived as obstructing the belief in and struggle for survival that was the ultimate goal of the new security practices.[13] By withholding the information of a person's nearing death the experience of dying was made impossible and the process of dying itself was in part eradicated. Though the rituals that once promised security in dying were lost, the process of dying remained "ritualized." However, today the rituals are often dominated by hospital routines, dictated by doctors and nurses and frequently aimed at life: the here not the beyond. So while the rituals and practices of dying have changed, the performances surrounding the process are still governed by protocols and scripts that are now controlled by (bio)medicine instead of religious dogma.

The "regime of silence," as the era dominated by the practice of withholding the knowledge of one's imminent death has been called, extended until the 1980s when more and more people perceived the security practices designed to cure and save life dictated by hospitals and medical staff as precarious.[14] Dying had become a fully medicalized phenomenon but instead of providing the promised security, the new practices lead to the incapacitation of the patients who in part started to feel threatened by the

12 Ariès asserts in a later publication that the arrival of the priest was delayed "until his appearance could no longer come as a surprise" (*Hour of Our Death* 562).

13 This awareness of death was not only important in religious considerations but represents the center piece of Heidegger's *Being and Time.* He defined the awareness of death, so the knowledge of one's end, as the core characteristic that distinguishes humans from animals. The denial of death that has dominated the second half of the 20th century would in that sense be the eradication of what makes us human. But Heidegger also stresses the importance of awareness in dying and approaching death in his existentialist philosophy by ascribing it the unique possibility of authenticity – the falling away of *Dasein* making *Sein* recognizable to the dying individual. He argues that dying is one's "ownmost" (Heidegger 294) and grants the individual the possibility of experiencing "an impassioned freedom towards death – a freedom which has been released from the Illusion [sic] of the 'they,' and which is factical, certain of itself, and anxious" (Heidegger 311). Today this notion of authenticity is echoed in bioethics stating that "[t]he approach to death offers the dying person a kind of understanding of himself that perhaps no other period in life can provide" (Curran 254).

14 Elisabeth Kübler-Ross was one of the first who broke the silence and denial of death and dying already in 1969 with *On Death and Dying*.

prescribed scripts of survival championed by the dominant biosecurity narrative. The hospice movement, amongst other reform movements for dying, called for a renewed awareness of dying to facilitate the possibility of dying well. And Psychological Studies have shown that the horror of death and dying today is the most intense it has ever been, which is often attributed to the lack of social ritual (Kübler-Ross, "Fear of Death" 211, Wouters).

The demand to reconsider and renegotiate the understanding of and attitudes toward dying represents a return to the older security narrative that centered around awareness and acceptance. Today, the time of dying is increasingly rendered as a time of preparation again, which includes arrangements that are in place to safeguard the dying as well as the bereaved. Though the practices today are thoroughly secularized, awareness represents again the prerequisite for the security practices in dying that promise the possibility of dying well. However, the importance of awareness is not directed (exclusively) toward the end point – so the security in the beyond – but the security during the process itself, as noted before. Acceptance as the proper and safe way to die, however, hinges on the awareness of dying to be able to follow "specific cultural scripts" (Seale, *Constructing Death* 40). The new security narratives not just problematize a lack of awareness, so the ignorance of one's impending death, but at the same time re-evaluate the life prolonging measures and the treatments that are focused on survival. The overall medicalization of life – the pillar of biosecurity – and the core practices of biosecurity are in the context of dying perceived as potential threats themselves. This becomes obvious when looking for example, at the changes in the "documents" preparing for one's death. While once the last will was the symbolic object preparing for death, the "living will" has become the modern addition to the testament. It was "instituted" in 1977 when California passed the "right-to-die" law, which allowed patients to be disconnected from life-prolonging technology and treatment, or to deny resuscitation. Though biosecurity practices are not a threat to life, they came to represent a threat to the person and their dignity.

The all-encompassing medicalization of society facilitated not only the prolongation of life and the changed attitudes toward dying, it further altered the process of dying by decisively lengthening it. Today "the average American male . . . is debilitated for five years before he dies, and the average female for eight years" (Hardwig 37). Hence the actual process of dying has changed fundamentally. The thanatologist Allan Kellehear points out that in some cases "the expectation of 'dying soon' comes and goes as a psychological and social experience and may do so – not over days or weeks – but perhaps years" ("On Dying" 389). The experience of dying is therefore oftentimes an experience of waiting for the end. Today, the rise of biomedicine as a normative power has been so radical that people are not only afraid of death, but of death not coming "quickly enough," or in other words of waiting for death for too long and of being overtreated.[15]

15 For the aged, Hardwig asserts that "the traditional fear of dying to soon" shifts to being "afraid that death will come too late" (Hardwig 37). And also in other cases, most famously Terri Schiavo's case, people are afraid of being kept alive – of becoming living corpses. In 2014 Compassion and Choice reported that 25 million people per year experience unwanted treatment.

Rather than the fear of dying too early, it becomes a question of dying in time, i.e. early enough so as not to lose dignity in suffering. Escaping the dominance of biosecurity with a living will, a do-not-resuscitate order, or the right to die represent the new practices of security in dying. They promise to ward off the loss of dignity and inhumanity that often seems to be encountered at the end of adhering to the gospel of biosecurity. Today, the positions within the medical community drift apart and are apparent in the distinction between "Hippocratic Medicine" and "New Medicine" (Colbert). While the former restricts its intervention to the alleviation and the withdrawal of life-prolonging measures, the latter supports PAD. The practice is legal in 11 states, based on the argument of unnecessary and inhumane suffering.[16]

The Hemlock Society is seen as a decisive factor in starting this development. Founded by Derek Humphrey in 1980 after the death of his wife the organization was renamed End of Life Choices in 2003 and merged in 2005 with the Compassion in Dying Federation to become Compassion and Choice.[17] Together with Death with Dignity they are the leading institutions advocating change to prevailing security narratives and practices of dying to legalize PAD as a crucial civil right. All of these shifts of understanding and practice are accompanied and facilitated by narrative efforts that render the (new) visions of security in dying. The documentary *How to Die in Oregon* is an example of such a narrative effort, which provides an exemplary narrative in which biosecurity practices of prolonging life become a threat to the security of the person.

Fearful Visions: The Threat of Dehumanization and the Relationality of (In)Security

> I would prefer not to
> *Herman Melville*

The HBO documentary *How to Die in Oregon* by Peter D. Richardson represents the security narrative of dying well facilitated by the practice of physician-assisted dying, or Death with Dignity as the practice is also called. The documentary was released in 2008 and won the Sundance Film Festival in 2011. It enters into a growing debate in the U.S. about the way to die well and the choices that should be available to dying individuals to guarantee security in dying. It is therefore part of a narrative effort advocating legal changes that allow for the widely prohibited practice in the first place. It does so by putting dying on screen, which a Sundance reviewer called "emotional, provocative stuff" (Chr. Campbell). The opening scene sets the tone for the documentary and represents without further introduction the deathbed scene of Roger Sagner in form of a handheld

16 In 1995 Oregon passed the Death with Dignity Act; in 2008 the Death with Dignity Act was approved in Washington and in Montana. Since then, eight more states have authorized the practice: Vermont, New Mexico, California, Colorado, Washington DC, Hawai'i, New Jersey, Maine, and New Mexico.

17 Compassion and Choice is an advocacy group that institutionally supports the practice in states that have enacted an act modeled on the Oregon Death with Dignity Act and organizes the struggle for legalizing the practices in states that have not.

home movie: him drinking the fatal medication, his last words, his last breath and finally his lifeless body. The narrative is roughly divided into two storylines. It tells the story of patients choosing to end their lives (and dying) by making use of the possibility granted by the Death with Dignity Act in Oregon. At the same time, it represents the activism of Compassion and Choice working to legalize PAD in Washington under Initiative I-1000. Each storyline follows primarily one personal testimony as representative for the group of the dying and the group of activists.

Cody Curtis is a 54-year-old woman diagnosed as terminally ill with recurring liver cancer and the main protagonist telling her story of dying well with Death with Dignity. She is supported in both, her dying and her storytelling, by her husband and two children (Jill and T.) as well as her doctor (Dr. Katherine Morris). Cody's narrative of dying safely is further contextualized with smaller episodes narrated by other dying individuals who also chose Death with Dignity. These short episodes of Roger Sagner, Gordon Green, Aideen Wakefield, Barbara Lucke, Peter Scott, Ray Carney, and Randy Stroop introduce the documentary and interlace the first half of it. They illustrate that PAD is not a rare occurrence but a well institutionalized practice in Oregon. The episodes are narratively connected by the Compassion and Choice volunteer Sue Dessayer Porter whom the documentary accompanies to home visits with most of these individuals. Her work also represents the bridge to the parallel main storyline represented by Nancy. She tells her story of becoming an activist and volunteer for the legalization of the practice in the state of Washington, which is successfully instituted at the end of the documentary. In doing so Nancy represents reiteratively the story of her husband's suffering in dying as a negative example of what happens if Death with Dignity is not available. The two narrative strands are woven together by the alternating exposition of Cody's dying and Nancy's activism. The combination of the two storylines represents both the personal as well as the political and institutional side of the security practice of physician-assisted dying.

In representing PAD as a benevolent and necessary practice (to protect security) the documentary constructs a narrative that needs to render a radically different understanding of security from the dominant narrative of biomedical salvation. To establish the legitimacy of the "new" security narrative, the threats to dying well have to be narrativized and made pervasive. Accordingly, the documentary represents what is at stake by establishing and re-defining the threat in dying not as death but as survival. Further prolongation of life threatens the loss of dignity caused by unnecessary suffering due to continued medical treatment and the uncontrollable corporeality in dying. The security promised formerly by life-prolonging measures is represented as standing in the way of security, so in the way of dying well and with dignity. The documentary therefore exemplifies the shift in the understanding of security where medical treatments turn from security practice to a fearful vision of humiliation and dehumanization.

The main storyline of Cody's dying starts after an introductory frame with a direct interview in which Cody reports how she was diagnosed with cancer (*How to Die* 16:54) and how her cancer returned. Cody's diagnosis of only "six months to live" based on the lack of effective treatment for her form of recurring liver cancer is, thus, foregrounded from the beginning on. This introductory information on Cody's medical history makes unmistakably clear that this woman will be dead soon and that the possibilities of biomedical security practices have been exhausted. While a cure and biomedical salvation are out of

reach, life prolonging measures are here represented as not only obsolete, but as potentially damaging. "95% she will only gain a couple of extra months, that will be a lot of extra pain, and a lot of extra cost" (*How to Die* 26:45) as Cody's son explains in one of his many interview fragments. The medical treatment and the inability of controlling the body in dying are understood as producing "extra pain," contributing to the likelihood of losing dignity in dying, thus representing insecurity.

Cody herself articulates it this way: "I would prefer not to die, thank you very much. But given that I know I am gonna die, is an extra three months of…em… fluid leaking through my pores sound that great? Well, no. I rather go when I am still feeling okay and when I can still communicate with my family" (*How to Die* 21:58). This interview segment is followed by Cody bending in pain, which embodies and manifests the severity of the threat the audience has just heard about. Since Cody's appearance does not otherwise indicate that she is sick and much less that she is dying, this *showing* of her pain – the inclusion of this scene in the documentary –is crucial to make visible the suffering and pain. But medical treatments are not only framed as prolonging suffering. The normative biosecurity practices are also represented as increasing a loss of self-determination:

> It's very comforting to have them [the medications] here. And I don't have to go through any more bureaucracy, or take another trip to the pharmacy, …em… they are here…It's whenever I decide. It's nothing that I have to do, it's not like in the hospital where I was told, "you have to have another CT scan," or "we are gonna take you down to do another procedure." It's my choice when to take them, and whether to take them. (*How to Die* 23:15)

The continuation of medical treatment is represented as merely facilitating more and longer suffering enhanced by the loss of self-determination within the symbolic space of security: the hospital. The biomedical practices geared toward saving life are thus clearly detached from the promise of security. The endurance of pain and struggle for survival is narrativized as unnecessary suffering since survival is unattainable and the prolongation of life does not promise the continuation of a quality of life. In foregrounding this threat the documentary shows that security relies on a normative understanding of the able body and is established in relationality to the other.

Security cannot be found in survival for survival's sake but is oriented toward the normative understanding of an able body. When Gordon reserves the right to die for the time when "I am wrecked up and in this bed" (*How to Die* 12:43) he articulates at what point his life would not be worth living anymore. The security narrative of dying well established in the documentary therefore makes clear that security is not just a promise of life, but of "good life." The narrative thereby also makes more obvious the normative understanding of corporeality that underlies this understanding of "good life." The documentary explains the reasons that lead to the decision of PAD as well as the necessary legal preparation "from buying to dying" by following the volunteer Sue Dessayer Porter of Compassion and Choice in her work with the prospective patients. Almost every interviewee foregrounds the fear of disability and suffering as the leading motivation for taking advantage of the Death with Dignity Act. Peter, one of the patients the documen-

tary introduces with the volunteer's home visits, explains: "I can still walk, but when that ends I will be making that decision" (*How to Die* 9:56).

In contrast to the loss of self-determination associated with continuing medical treatment, the interviews with the dying stress that the individuals seek a form of control, which is also indicated in sociological studies of the Death with Dignity practice.[18] The Compassion and Choice volunteer articulates the desire most explicitly: "These people have lost so much control. And they will tell us repeatedly that they want the medication for control" (*How to Die* 9:23). Throughout the different parts of the documentary the endurance of pain and suffering in dying is represented as unbearable and inhumane because of its uncontrollability. Likewise, in the scenes dedicated to the legalization of the practice represented by Nancy this question of controlling or managing suffering in dying is central. When Nancy's co-interviewee on a radio show cautions that she is troubled by the practice since there are so many things that can be done to alleviate suffering, Nancy responds: "There are diseases where you cannot control it, my husband had one of those, and that is why it should be an option" (*How to Die* 50:33). The documentary leaves this question with Nancy's explanation and her opinion as the last word. The threat in dying is mainly marked by the suffering of the individual and the declining materiality of the body that proves uncontrollable and therefore threatening the dignity of the individual.

The driving force in both main storylines – Cody's dying and Nancy's activism – is the impaired body, the loss of control over bodily functions, and the reliance on care. Loss of dignity is thus also described as the loss of agency due to the debilitated body which serve as the negative horizon of dying well taking advantage of the possibility of PAD. In Nancy's case it is the memory of her husband's agonizing suffering in dying, which motivates her to dedicate herself to the Death with Dignity movement. The narrative of her husband's process of dying is the counterpart to Cody's experiences leading up to her decision for Death with Dignity. Losing dignity is in both these stories based on the physicality of dying and the increasingly debilitating body. The threat of losing dignity is made present by the reiterative narration of the impaired body, however, it narratively only exist either retrospectively or in anticipation.

The dehumanization in dying is made tangible through Nancy's witness account of her husband's dying. She reports the excruciating pains her husband had to suffer without the availability of Death with Dignity. Introduced halfway through the documentary (*How to Die* 35:00) her story is characterized by slow piano music in a minor key, setting the mood for the portrayal of how her husband wanted to die but couldn't – or rather wasn't allowed to. She details his suffering in dying as torment that could have and should

18 A study on the leading reasons for seeking physician-assisted dying states that the "most frequently reported concern among patients include loss of autonomy (90%), loss of meaningful activities (88%), loss of dignity (84%), and loss of bodily function control (57%)" (Drum et al. 5). While most people die confined to their bed, "[s]eventy-nine percent of DWD patients did not wait until they were bedridden to ingest lethal medication" (ibid. 6). They even state that "physicians perceived their patient's desire for DWD as stemming from the patients' inability to adjust to disability" (ibid. 7). Courtney S. Campbell and Jessica C. Cox elaborate in their 2010 paper "Hospice and Physician-Assisted Death: Collaboration, Compliance and Complicity" that the large majority (88.2 % to 95.1 %) of patients who decide for PAD already receive "high quality palliative care" (27).

have been prevented: "He was in a hospital bed, he couldn't control his arms, probably worst was that he became incontinent and he had to be in diapers. He hated that. He lost his vision and then his eyes started popping out from the tumors so he couldn't close his eyes" (*How to Die* 35:14). The threat of dying within the system of biosecurity is described by Nancy retrospectively as a dehumanizing process. Showing pictures of before and during his dying Nancy describes his visible outward bodily change as the transformation of a "50-year-old man into an 80-year-old man within just a year" (*How to Die* 36:00). The narrative thus relies on the reading of the body in dying to describe the loss of dignity and testify to the failure of available biosecurity practices. Nancy's reading of the body in dying shows that the body and bodily security is indeed performative most forcefully so in its disguise as natural as Butler puts it ("Performative Acts" 522). Neither Nancy nor the documentary in general explains why for instance incontinence should be regarded as inhumane. Without a further elaboration this meaning is represented as if it was inherent in the materiality. Since it follows a well-established discourse of the able and controllable body that "naturally" opposes the impaired body the missing explanation does not produce a break in the narrative but seems like a logical causal narration.

The understanding of a certain kind of impairment as dehumanizing and unnecessary, while others such as depression, are not, shows that the visibility on the body surface, a material deterioration is crucial for our understanding of security in dying. It further shows that this materiality should not be simply understood as a natural entity but rather as a performatively established meaning. Butler rethinks the relation of body and power in which "the fixity of the body, its contours, its movements, will be fully material, but materiality will be rethought as the effect of power, as power's most productive effect" (*Bodies* 2). The suffering in dying can therefore not be understood outside of pre-established categories of meaning that are recognized in the performance of the body. Though the body in dying does not enact the demands of an internalized power discourse, the understanding of what is dehumanizing very much does. What is frequently represented as the bodily expression that follows a natural order are instead "socially instituted and maintained norms of intelligibility" (Butler, *Gender Trouble* 23). The security read in the materiality of the dying body as something dehumanizing thus needs to be acknowledged as pre-established cultural categories that are applied to the body rather than an inherent meaning.

The understanding of what (in)security in dying is thus depends on the construction of a narrative that has an author, aim and perspective. It is therefore important to always keep in mind what Spivak calls the "place of 'interest'" (279)[19] when looking at security narratives of dying and at the claims of a normal in contrast to a dehumanizing body. In the documentary the dehumanized suffering body serves as a comparative horizon to legitimize the claims to what constitutes security. The problems and pitfalls of the security practice of Death with Dignity remain unquestioned in the documentary in the same

19 Spivak criticizes the position of intellectuals speaking for and representing so-called subaltern individuals problematizing invisibility of their speaking position: "intellectuals, who are neither of these S/subjects, become transparent in the relay race, for they merely report on the nonrepresented subject and analyze (without analyzing) the workings of (the unnamed Subject irreducibly presupposed by) power and desire. The produced 'transparency' marks the place of 'interest'" (279).

way that the underlying assumptions of good and bad death, or the sheer possibility of dehumanization in dying remain uncontested. The documentary does not confront what exactly is implied when Cody says she will opt for Death with Dignity when "her life isn't worth living anymore" (*How to Die* 23:23), which keeps the security narrative supporting the practice of physician-assisted dying straight forward and easier to understand.

The juxtaposition of Nancy's husband's dying and the narratives of those being able to choose Death with Dignity establishes dying without the security practice as unnecessary suffering for the patient as well as for the caregiving family. Though the documentary renders the process of dying as much more than "just" a material process of bodily decline, the physicality is represented as significant, if not determining the impact on the individual's life and willingness to live, as shown above. This understanding of physical decline is not a solitary process but very much a social one. The sociologist Clive Seale suggests understanding "the 'bodily' symptoms as the body's communicative interjection into social life" (*Constructing Death* 2). This emphasizes that the body and its projected trajectory in dying are not just "read" and evaluated by the dying individual but also by others, whose perspective is reflected in the opinions voiced by the dying. Cody, for instance, claims that, "I will not be humiliated with losing control of my bodily functions again" (*How to Die* 28:25). The humiliation feared and anticipated is based on the implied audience of the process of dying. It relies on shame which is an inherently relational affect and an important force in the understanding of security, as well as in the dying person's experience. Cody's assertion that "this will be tidy" is therefore not only referring to the security of the dying self but to the witnessing other.

The control and eradication of the uncertainty of dying is paired with its relationality to the other: "it is a weird limbo…except with Death with Dignity you know what's going to happen and you can give that to your family" (*How to Die* 24:15). Cody asserts again and again that "I don't wanna put my children through that;"[20] "I'll come to the point where I am not enjoying things and I am a burden" (*How to Die* 1:15:04). Cody's repeated mentioning of her responsibility toward her family is also mirrored in Gordon's position, who asserts that "I just wanna lie down and never wake up. And do the decent thing. Once in my life I will be decent" (*How to Die* 15:17) looking at his uncomfortably smiling wife. This fear of becoming a burden represents what Kellehear has termed in *The Social History of Dying* "Birth of the Shameful Death" (213), where "[t]iming [d]eath" (234) becomes an important and complex exercise. This timing of death is governed by the security narrative, which determines the appropriateness of practices and the exact moment when this appropriateness ends. The security of the self in dying is not just contingent on the experience of suffering but seems to be understood through the "gaze" of the other. Security, in other words, is defined in relationality. Cody's son puts this relationality into words when he explains: "She [Cody] is also very dignified. And when she looks sick that

20 This comes in response to Cody telling the volunteer in tears that "I am really afraid of being a coward at the end" (1:02:46), which is answered with "we call it death with dignity not death with cowardice. Do you think its coward to die instead of suffer? That is a message our society gives over and over again; that only, hm … if you…, that only the truly courageous are the ones willing to suffer" (*How to Die* 1:03:02).

is very hard for her because she wants to present herself as being healthy" (*How to Die* 21:23). The insecurity caused and "revealed" by the body to others is thus crucial.

The humiliation associated with the failing body in the documentary thus shows that it is not just the reading of the self and an intimate feeling of suffering but also the reading of others – family, friends, caregivers – that influences the experience of dignity in dying. And it is this relationality between self and other that ultimately defines security/insecurity. The documentary thus exemplifies that the intangible fear of death is often eclipsed by more mundane fears. The fear of death and of suffering in dying are further increased by social expectations as sociologists such as Charles O. Jackson point out: "Individuals die through a whole cluster of societal definitions and value-laden categories. The worth of their particular type of death is assessed. . . . Social assignment is made also on the 'appropriateness' of death" (4f). The documentary thus shows that suffering in dying is exceedingly influenced by society. Dying thus materializes through the encounter during the process: between self and body as much as between dying and those present and witnessing. Though the regression in dying is pathologized and is not attributed to the responsibility of the sufferer in the documentary, it nonetheless seems inherently connected to the feeling of humiliation and shame.[21] The complexities of security in dying therefore indicate a change in materiality, medical technology, and the ever-growing presence and importance of bio-medicine in U.S. culture and society. They also indicate a changing relation to "what is human," what is dignified, what is the "we." And this "we" is reinforced in affective terms against the ostracized other.

The affects attached to the deteriorating body, such as shame and humiliation function similarly to affects in national discourse as Sara Ahmed has described it in "Politics of Bad Feeling."[22] Ahmed asserts that "[e]xposing the failure of the ideal is politically important" ("Politics" 79) because it reinforces the ideal, not in representing it but in defining what its opposite is. The representation of the feared dehumanizing bad death thus reinforces the border between good life and unlivable life, between proper and improper "decline." It is this exclusion from a "normal" and good life that defines the question of when a life is not worth living (anymore).

Since the other is so important in negotiating the meaning of dying and its evaluation, the act of witnessing plays a crucial role in establishing the security narrative in the documentary. The representation of loss of dignity in dying, so the representation of insecurity, relies largely on Nancy's witness account which she represents in the interviews. Her husband might have experienced his dying as excruciating and humiliating, but it is Nancy's witness account of reading and interpreting his body that defines

21 This shows that the affects determining the worth of a death are never only the feelings and experiences of the dying patient, but also those of the relatives or friends and of healthcare professionals. Emotions regarded as a "window to the truth" or "a different kind of intelligence about the world," as Nigel Thrift calls this perspective (60), are therefore problematic. Thus, I would rather suggest that the process mainly materializes in the affective encounter between self and other and dying materiality, an encounter of almost compulsory assessment.

22 Ahmed asserts in the context of the "National Sorry Day" in Australia that the expression of negative feelings such as shame toward the failures of the nation does not only reveal acknowledge the negative but at the same time reaffirms the positive qualities of the nation and therefore reestablishes an ideal rather than deconstructing it.

his loss of dignity. This reading and interpreting of the body shows that the drama of security in dying is played by the body as actor while the dying self and the attendees represent an audience that is reading the body for (in)security. The notion of theatrical performance is thus profoundly important for the understanding of security in dying inscribing a structure of witnessing and staging. The narrative construction of threat/insecurity in dying thus relies on the bodily process as a performative act. It can be regarded as a performative act because it is staged and closely observed by doctors, friends, and family – if present – and the self. Though the deteriorating body thwarts any intentionality of the subject, the corporeality is always and already in society, always on display, "impressed upon by others, impinging upon them as well" (Butler, *Precarious* 27). As such bodily decline relies on similar structures as staged theatrical performances of spectator and actor. As performativity is essentially based on communication to produce its effect it requires a second person that is similar to Austin's interlocutor.

Narratives of death and dying usually rely on the witness of dying to establish the "survivor's tale" retrospectively after the death of the individual, as represented by Nancy's story line. In the security narrative of physician-assisted dying represented in *How to Die in Oregon* this temporality is reversed, since the loss of dignity is a future threat. The retrospective narrative is turned into a proleptic narrative of what would or could happen without the access to the security practice of PAD. In the security narrative of dying well provided by the documentary the feared loss of dignity is not experienced and therefore not present. It represents a threat that can and has to be foreclosed by the security practice. The narrative construction of the threat therefore relies on anticipation, which is marked by fear. As previously argued, the modern way of dying is more frequently than not a process of waiting, an anticipation determined by expert knowledge, diagnosis, and prognosis. The perspective dominates the documentary which takes place in this temporal space of anticipation. It uses this temporality in its narrative perspective to establish the security narrative of dying well. Dying is represented, as in Thanatology, by emotions – mainly pain,[23] fear, and distress – which are caused by the prospect of the deteriorating body.[24]

This fear is in part based on past experiences of suffering, which foreshadow the potential menace of losing dignity. The threat of "losing dignity" in dying is exemplified by the retrospective narrative of Cody's diagnosis and her suffering after the first surgery. Within Cody's story the retrospective narrative of her illness narrative serves to foreshadow the expectations for her potential future. Images of Cody in a coma after her first surgery and her suffering during recovery are shown in a photo montage with her voice-over explaining her bad surgery results. The scene is summarized by her husband's recollection of her saying that "I don't want another night like that" (*How to Die* 18:26). The

23 In the 1964 Cicely Saunders published the article "The symptomatic treatment of incurable malignant disease" which challenged conceptions of what causes the suffering in dying with her concept of "total pain." This approach recognizes "not only physical symptoms but also mental distress and social or spiritual problems" as constituents when describing the pain of dying for the diseased individuals (C. Saunders 430).

24 In dying, affects, as expressions of inner feelings, are often the main source of "knowledge" about the process. Many studies, such as Kübler-Ross' interviews with the dying, define dying in affective stages such as anger or depression.

narrative of suffering is so forceful that the discovery of new signs of cancer literally represents the decision for the security practice of assisted dying in the documentary. Temporally, this mirrors the pre-emptive logic of the security narratives in previous chapters. The narrative of past suffering makes the potential future suffering of the final stages of dying present and to a certain extent experienceable. In more abstract terms this means that a projected future (threat) is narratively made present triggering an action in the present to foreclose this future.

The temporality that defines Cody's experience and her decision to take advantage of the Death with Dignity Act is also emblematic of all other stories of the dying. It is the potential future threat that is estimated according to a comparative horizon. What in Cody's case is represented by her illness experience is Gordon's experience of his father's dying: "I saw my dad twelve years with a stroke and one whole side was gone … and he just kept saying 'I just want out'…" (*How to Die* 13:12). "But I'll handle it until something like that happens" (*How to Die* 13:27). The narrativization of this past suffering makes present the future threat which is then foreclosed by the security practice of physician-assisted dying. The practice eradicates the uncertainty of "nature taking its course," which is contrasted by the desire to control and author one's own death. This also shows that also the security narrative of dying well with physician-assisted dying follows a pre-emptive logic of security.

The narrative of suffering is represented interchangeably with scenes of happy family life as a competing narrative representing security. Cody's assertion that "we did not let animals suffer" (*How to Die* 21:24) is concluded with a cut to photos of her happy and healthy. The feared suffering represents the comparative horizon for the effective narrative of the new security promise of dying well.

The Promise of Security and the Proper Way to Die: Agency, Choice, and Acceptance

> he raised the cup to his lips and cheerfully and quietly drained it. I have heard it is best to die in silence. Keep quiet and be brave.
> *Plato*

Physician-assisted dying promises security in dying in form of dignity, controllability, and agency. The beginning of the documentary, which shows Roger Sagner's dying at home after drinking the prescribed medication represents this opposition clearly, as I previously argued. This prelude offers a shocking and highly emotional scene since the audience witnesses Roger's last moments of dying and his death, which is a rarely staged moment and an unfamiliar one for most people. However, the scene becomes an emotionally ambiguous one as Roger states that "it [the medication] will kill me and make me happy" (*How to Die* 2:08). This "last act" serves as introduction and frame for the main narrative. It establishes death as welcomed and the practice of taking one's own life as security. The first thing the viewer learns is that Death with Dignity is not an imposed practice but an individual choice, which is experienced as a blessing by the individual.

The practice represents the promise of security, showcasing the controllability of the body and agency of the individual which is established in opposition to the negative horizon of humiliating and uncontrollable bodily decline, discussed above. But the re-interpretation of death – the moment that otherwise represents and manifests insecurity – is more complex than showing one scene of a self-administered death. It relies on the narrative construction to establish agency and acceptance as core constituent of security in dying. This renegotiation of security in dying represents a return to core elements of dying well that preceded the rise of biomedicine as the arbiter of security and its all encompassing promise of controllability. The documentary foregrounds agency and choice as well as awareness and acceptance as the foundational pillars for security in this last passage of life.

In order to represent PAD as a way to die well it is fundamental to divorce the security practice from its negative connotations, especially suicide. Already the name of the security practice used in the documentary exemplifies this detachment. The interviewees consistently use the term physician-assisted dying instead of physician-assisted suicide.[25] This choice of nomenclature linguistically separates the association of suicide from the security practice and thereby detaches it also from the moral judgment of suicide as a cowardly and selfish act that is condemned by religious groups and society at large. Nancy puts the importance of this distinction into focus in an interview with a Canadian journalist: "No, it's very offensive to me to call it suicide. Suicide is something someone does who is otherwise physically healthy and has their life ahead of them, is clinically depressed and don't [sic] wanna live" (*How to Die* 50:58). In this representation the stigma attached to suicide remains unchallenged. Instead of denouncing the narratives condemning the act of ending one's own life altogether, suicide is pathologized and represented as mental illness while PAD is rigidly separated from this practice. This distinction between "sick" behavior, compulsively enacted by non-competent individuals and the rational choice for medical aid in dying is crucial. It creates a definitive dichotomy of good and bad forms of ending one's life, or rather of good dying in contrast to bad suicide. Suicide as such remains configured as a threat to the individual, a preventable tragedy and failure based on irrational or pathological problems – something to be averted. In contrast, in the security practice of PAD the act of killing oneself becomes exemplary for "good dying" and a salvation of the individual from the irredeemable body suffering from physical health problems.[26] In fact, Death with Dignity becomes the epitome of good death as the term euthanasia would literally indicate. However, the history of involuntary euthanasia makes this terminological link problematic as well.

Not surprisingly then, the practice is also disassociated from the dark past of euthanasia and the term euthanasia as such. Studies have shown higher public approval

25 The organization Death with Dignity dedicates an extra page on the website to the "Terminology of Assisted Dying" insisting on the importance of using value-neutral language, which is not hurtful to patients and their families.

26 The invisible suffering from mental illness in Nancy's explanations is not acceptable as a legitimate reason to choose death.

ratings for PAD when promotional texts do not use the term euthanasia.[27] The movements institutionally supporting the practice and its further dissemination are therefore meaningfully named Compassion and Choice and Death with Dignity. The practices of euthanasia of the past are not explicitly mentioned but any connection to coercion, persuasion, or intimidation is eradicated by an insistence on the agency of the individuals choosing Death with Dignity. The documentary stresses again and again that the practice is not based on coercion but free will and that it is a choice that is not violating rights but representing a right itself. The security narrative of the documentary therefore stresses not only the inhumane and unnecessary "suffering" experienced without the security practice of PAD but the agency of the individuals using Death with Dignity.

Agency is primarily foregrounded by marking the practice as an empowering choice of individuals. This choice for security in dying is emphasized and detailed in the depiction of the home visits of the Compassion and Choice volunteer Sue Dessayer Porter. The short episodes reveal single steps in securing the right to die at a chosen moment averting the otherwise seemingly inevitable humiliation and loss of dignity encountered in dying. Dying is here not constructed as "the self coming to an end" but as an active "ending of the self." Security is based on individual active decisions and therefore on the responsibility of the self. The responsibilization for the self thus reaches beyond the obligation to stay healthy to the process of dying and how one dies. After the first scene at Roger's deathbed, Gordon is accompanied on the way to the pharmacy to buy the prescribed drug and is then shown calling the volunteer to inform her that he has obtained the medication; and Aideen is informed about which drink she should purchase as there are two options – "Nembutal costs over a thousand dollars, Seconal is 130 dollars" (*How to Die* 11:46). It is made clear that PAD is not a quick and easy act possible on an impulse by a suffering individual, nor a "fast way out" that is imposed on a helpless individual by others. PAD is represented as a practice that requires extensive organizational and logistic effort on part of the dying as self-reliant responsible subjects.

The detailed representation of the practice in the documentary shows that security in dying does not rely on one but on multiple choices, each one representing a step of an able individual on the way to security in a pre-emptive sense. After deciding to take advantage of Death with Dignity the further necessary choices for security consist in obtaining a prescription for the medication and the decision if and when to take it. The patient thus pre-emptively gets a drug in case suffering becomes unbearable for the individual and then pre-emptively takes the medication to foreclose the possibility of losing one's dignity. Every step is marked by agency and self-reliance stressing the importance of bioliterate subjects and the care of the self. To prepare and provide for one's end is thus decisively the responsibility of the individual.

In addition to the insistence of choice and agency, the security practice of physician-assisted dying needs to eradicate any suspicion of coercion, especially hidden and implicit forms such as social expectations, or purely financial considerations. Each episode stresses the agency and choice of the practice, as the volunteer explains: "There is a fine

27 The Hasting's Center Report in 2010 asserts that "Field testing prior to passage of the Oregon law in 1994 disclosed that when the process was described as "suicide" or as a form of "euthanasia," popular support declined by 10 to 12 percent" (Campbell and Cox 28f).

line of never ever wanting to think that we are selling a process here. We are not. We are offering a choice" (*How to Die* 11:02). By representing the practice as a rational and institutionalized choice it is further detached from its negative connotations which are judged as irrational or non-consensual acts. When Porter states that "we represent choice not death" (*How to Die* 13:39) she articulates the walk on a tightrope when it comes to defining assisted dying as a security practice. Her interview scenes highlight the importance of precluding any accusation of coercion in the very carefully formulated sentences informing the individuals about the different details of the practice. She uses almost formulaic phrases such as "If you were ever to make the choice to take this medication" (*How to Die* 13:47). Porter says this to Gordon, who already has the drugs at home and has clearly made the choice. She thereby highlights her consulting role which remains in all comments impartial, neutral and in the conditional when referring to the act of ending one's life. All these carefully selected scenes place the (mentally) able subject at the center of the practice.

To protect individuals from coercion the Death with Dignity Act prescribes that patients have to be of sound mind and be able to self-administer the drug. The documentary recreates this guarantee of the free will and choice in its narrative construction, especially its voice. The documentary is carefully narrated and constructed *as if* told by the people themselves and has no traditional voice-over narration. Subjectivity and free will are thus represented in the voice of the individuals providing their own narratives.[28] This is achieved by the exclusive use of direct testimonials combined with a "fly on the wall" perspective. Large parts of the documentary are structured by "behind-the-scene" elements. The audience accompanies Cody into the hospital, the volunteer to her home visits and witnesses Nancy's activism. As a "character-driven documentary" it "approach[es] broader issues through one or a few social actors; that is, they combine the typing, portrait, and testimonial functions that other documentaries might keep separate" (Cagle 56). In doing so the director mirrors the core method in the study of dying applied in the different fields of Thanatology. Many studies are conducted as interviews with the dying or their caretakers, such as Kübler-Ross's famous "Interviews with the Dying."[29] The narrative voice of the documentary echoes this structure of "learning from the dying" which represents the dying as "native informants" for the still healthy. The voices of these native informants are pivotal in contradicting the established security narrative of biomedical salvation, and embodying free will and choice.

The narrative voice emulates, or attempts to aesthetically increase, authenticity by representing the dying as experts, and their stories as undeniable truth. The narrative of the documentary aims to capture the "authentic" experience by "showing" and thereby

28 Bill Nichols provides a historically oriented classification for distinct documentary styles: the "direct-address style of the Griersonian tradition" ("The Voice" 17), the "*cinéma vérité films*" *(ibid.)*, the interview-based documentary as "direct-address," and the reflective documentary, which "mixes observational passages with interviews, the voice-over of the film-maker with intertitles" ("The Voice" 18).

29 Elizabeth Kübler-Ross is one of the pioneers of studying and reforming the modern practice of dying. Her psychological studies, such as *On Death and Dying*, established a five-stage model of dying comparable to the process of mourning, a crucial period at the end of life which needs professional attention.

revealing the "truth." The stories represent the lessons to be learned from the dying themselves. The documentary genre in general is a narrative formation aiming "to represent 'things as they are'" (Nichols, "The Voice" 17). Or rather, as Patricia Aufderheide claims, "[a]ll documentary conventions . . . arise from the need to convince the viewer of the authenticity of what they are being told" (11). In *How to Die in Oregon* interviews with experts that are typically used to guarantee the veracity of what is shown are replaced by the dying themselves. Their comments on their own intimate experiences therefore substitute the expert talk *about* the experience. Thus, Richardson uses the aesthetics of the documentary genre to "provide" authenticity by testimonial narratives as an almost uncontestable "real."

The aesthetic strategy aims to reinforce the semblance of unaltered reality, and thus actively obscures its constructedness and the narrative agency of the director. Though the documentary style aesthetically enhances a "truth value," selection and edits are creating a version of the truth as much as a "traditional" narration would. The narrative develops its argument in an inductive structure, by showing evidence of the "beneficial" value of Death with Dignity. The audience follows the different personal stories, their perspectives, and their relation to Death with Dignity. The observational structure of the documentary furthers this implicit exposition. The direct interviews that represent about half of the documentary hide the interview situation. The face and voice of the film-maker remain invisible and silent, though the testimonies clearly emerge out of interview situations.[30] The testimonial narratives dominate the aesthetics while the editing controls the narrative by cuts, voice-over, and establishing the timeline. In other words, by assembling the selected material it determines the meaning of the story.

Nonetheless, by giving a voice to those who often remain unheard when dying and death are discussed, the dying are represented as subjects rather than objects of the security narrative of dying well. In the narrative representation the dying individuals, and in particular Cody, therefore preside over their dying as a governing agent similarly to how it was practiced in the traditional deathbed scenes. This representation of the new security practice of Death with Dignity approximates, and appropriates the old security practice of the deathbed, adapting it to the modern way of dying. The passivity of the "sick role" (Parson) dominated by medical procedures is narratively substituted by activity and subjectivity represented by the individual's role in their dying. But the dying are not only narratively re-constructed as the agentic subjects of their dying, equally important for the rendering of security in dying is their attitude towards dying as acceptance.

The native informants vouch for free will and choice and serve as examples of what dying well looks like. To provide a narrative in which suicide becomes the convincing way to "die well" and with dignity the documentary relies once again on its expositional character: Cody's dying exemplifies what good, and thereby dignified dying is. Her process of dying represents the competing narrative to the suffering and fear attached to the images of hospital routines. Her process is visually accompanied by nature scenes that dominate the largest part of her dying. Cody is shown on strolls through woods, walks on the beach, and working in the garden. The information that she plans to take the Seconal on Memorial Day (25th of May) (*How to Die* 23:23) is visually accompanied by an

30 There are but a couple of instances where the voice of the director enters the narrative.

ocean scene. The security practice is thus visually described by nature. Though physician-assisted dying cannot be described as nature taking its course, it is nonetheless aesthetically represented as natural in contrast to the "artificial" interventions in a hospital setting. The documentary consistently reiterates the opposition of uncontrollable suffering with the planned and peaceful farewell facilitated by the security practice of Death with Dignity. Though not without grief and mourning – every member of the family is shown or interviewed in tears – the peacefulness of the wide nature scenes lends their grief a righteousness; it is represented as the "proper" or "appropriate" performance in response to inevitable death: the healthy way to act. Dying well with PAD is thus able to circumvent the threat foreshadowed by the past suffering that is marked by distress, panic, fear, and uncertainty.

This representation of Death with Dignity shares a crucial aspect with the older (religious) understanding of security in dying though the current form is characterized as a completely secularized practice – and in fact is opposed by most religions. The narrative stresses that dying is more than merely a biologically determined end, but rather a closure of a person's life, which relies on awareness and acceptance. Rather than the ending of a person, Cody's story reflects the active "bringing to an end of the person." She is introduced as she crosses off things from her Bucket List (*How to Die* 16:04), saying farewell, and giving away things. She is aware of her nearing end and is able to close her own life (narrative) by telling her own story. It is thus not only the materiality of dying – the suffering – that determines the understanding of (in)security, but also the prescribed attitude toward and behavior in dying. Her dying embodies and exemplifies this acceptance when Cody is still feeling well, but, more importantly, also closely before her last act of drinking Seconal. Her liver has begun to fail and Cody is shown in her physical suffering, while appearing mentally stable and in good spirits. She teaches her son the family Christmas cookie recipe and the camera team accompanies her to the hairdresser for a last haircut. She is shown in an over-the-shoulder shot in the mirror while her hair is being cut with a voice-over providing her reflections on dying (*How to Die* 1:25-35). Cody closes her own narrative by telling her story in the documentary and by deciding actively how she will be remembered. Her process of dying represents what she asserts already early in the documentary: "everything will be fine; I've written them letters" (*How to Die* 27:43). The ability to close one's own life narrative mirrors the prescribed "healthy" behavior in dying also foregrounded in thanatological studies supporting pastoral interventions such as "life review conduct."[31]

This positive nature of awareness and acceptance as a healthy and proper conduct in dying is further accentuated by the musical score that characterizes the different scenes of dying. In contrast to Nancy's and her husband's musical characterization, Death with Dignity is introduced with the comparatively "happy" folk song "In My Time of Dyin[sic]" performed by Tom Brosseau (*How to Die* 4:39-7:00). Creating the mood for the scenes representing self-administered death with a folk adaptation of a Psalm might seem counter-intuitive as it expresses the most fervent opposition to physician-assisted dying. But it

31 Cody's dying exemplifies this acceptance that is also defined as the good way to die in Thanatological Studies. It represents the possibility to reconstruct biographies and can also be seen as a form of narrative healing, so a security practice itself.

directly associates the "easy" and good death found with Jesus's help and the good death represented in the documentary. The soundtrack further underlines that the claim to dignity that the documentary makes draws on centuries-old cultural narratives of dying well, meaning dying prepared and aware of one's death, which has been reiterated in newer thanatological versions of the same narrative. Security in dying is here understood as awareness and consciousness, as a conclusion to life that reflects (on) the person. It represents a reversal of the denial of death and dying that dominated up to the 1980s as described before. Every dying protagonist who decides to take advantage of PAD represents this awareness in dying. They know they are dying and have accepted their "fate."

The documentary further stresses the necessity of acceptance as the proper way to die well by juxtaposing it with two short episodes of dying without taking advantage of Death with Dignity. The documentary allows a short glimpse of the feared downside of the practice. It dedicates four minutes to the problematic eventuality that people would be expected to use the Death with Dignity law as a form of implicit coercion. In showing "The Other Side" the documentary cuts to a Trailer Park (*How to Die* 52:06) which marks a different socio-economic environment than that of the other characters. Randy Stroup has final stage prostate cancer and reads out a letter which informs him that his Medicaid only covers palliative care or physician-assisted dying but no further treatment. Randy is angry and desperate, offering a contrasting understanding of dignity: "dignity means to me that I can hold my head up high and I can't see how anyone can take [sic] through life and hold your head up high while doing this" (*How to Die* 55:00). What could have instigated an interesting discussion on the different visions of "dying well" is cut short in favor of a clear cut security narrative in which awareness as well as acceptance are crucial to dying well. Randy's story ends after a few minutes with a black panel explaining that after his strong objection to PAD he received another round of aggressive treatment, yet died shortly after nonetheless. His experience and behavior in dying is marked by denial, which is not untypical for the process of dying,[32] but it is here clearly depicted as "harmful." The story of his dying is not further represented. The meaning and affective charge of his dying is dictated by the intertitle following his story: "Despite receiving chemotherapy treatment for 4 weeks, Randy died from cancer" (*How to Die* 55:16). His dying while fighting the disease with aggressive and physically debilitating treatment is represented as pitiful and unnecessary, ever more so as the security of dying well would have been accessible had he taken the right choice for security. The omission of his story's exposition represents the general exclusion of "another truth."

In contrast, Ray Carney's dying, which also occurs without the use of the medication, is defined by "self-determination" (*How to Die* 55.20). He has fully accepted his diagnosis, has obtained the prescription drug to end his life and is planning his own funeral (58:00). In contrast to Randy, Ray was only diagnosed as terminally ill with an estimated

32 According to psychoanalysis, the fear of death is motivated by the inherent denial of one's own death because "in the unconscious every one of us is convinced of his own immortality" (Freud, "Thoughts" 291). This notion is psychoanalytically attributed to the impossibility to think our own death, and indeed Kübler-Ross describes denial as the initial phase in her five-stage model of dying. She cites multiple interviews in which the patients, in rare cases until the very end, deny the possibility of their own passing with words such as: "no, not me, it cannot be true" (*On Death* 51).

six months to live because he refused the offered treatment to save or at least prolong his life – the removal of his voice box. His voice and voice box are central parts of his identity as Ray, a former TV host and singer, explains, and he cannot imagine a life without it. He declines treatment as it would mean a radical loss of an essential part of his identity. Ray is interviewed and accompanied to the studio where he records his own eulogy. His story also ends with a panel information: "Ray never had his voice box removed. / He died in hospital, physically unable to give himself the lethal doses of Seconal, a requirement of the Oregon law. / His eulogy was played" (*How to Die* 1:00:49). While tragic all the same, as he was not able to fulfill his wish and take the medication, his acceptance in dying nonetheless marks his process of dying as good and dignified; even triumphant as he defied the biosecurity narrative of survival which prescribed further treatment. He *chose* to die without having his voice box removed and closed his own life narrative. The juxtaposition of the two dying narratives of Ray and Randy reveal the normativity of the performance of dying in security. It is not the biological facts of dying that can be judged as inherently good or bad, but it is the behavior and attitude of the dying person.

The acceptance of death as the proper performance of security in dying is further accentuated in the conclusion of the documentary, which ends with Cody's deathbed scene. This scene is introduced by an intertitle that only reads "Saturday," two days before the set date for ending Cody's life. In the last days preparing for the final act Cody's suffering is shown close-up, highlighting the corporeality of the threat Cody is preempting (*How to Die* 1:32:42-1:34:36). Though her deathbed scene depicts grief, pain, and crying, it is explicitly marked as happy: "You must not think that only because I am crying it's not happy" (*How to Die* 1:38:45). The next intertitle reads "Monday" (*How to Die* 1:38:54) and introduces the final gathering: the house is shown from the outside, it is dark and only the windows are lit. The preparation of the drink is shown while the actual deathbed scene is represented by the audio from inside and the image of the window from the outside. It depicts a deathbed scene with singing, thanking, crying, the act of drinking the medication and heavy breathing. The scene culminates in Cody's last words: "This is so easy; I wish people knew how easy this was" (*How to Die* 1:44:10). The documentary ends with almost the same words that opened the documentary representing the iconic convention of last words.[33] The symbolic meaning that is according to Diana Fuss traditionally bestowed onto these words is here emphasizing the final truth of something that will remain forever out of reach for the living: the moment of truth associated with death.[34]

The last part of her long process of dying represents a return to the "beautiful death" of 19th century *sentimentalism*. The documentary represents an iconographic deathbed scene as the climax of the security narrative serving as *the* example of good and dignified dying, which is depicted as peaceful and natural, and strangely culturally familiar. Cody's deathbed scene echoes the iconic deathbed scene of the "beautiful death" (Ariès, *Hour of*

33 Despite the invisibility of the deathbed today "the convention of last words survives into the present, outliving the circumstances that produced it" (Fuss 894), which reveals the importance they have for our concept of dying.

34 This moment of truth is important in the concept of death and dying in religious and spiritual as much as in secularized understandings. As previously noted, also in Heidegger's existential philosophy death held the promise of truth.

Our Death 473) that for instance Harriet Beecher Stowe has enshrined in her depiction of Little Eva's dying. In this sentimentalist rendering death is not only beautiful, it is triumphant; instead of doubtful anxiety, Eva dies happily and in a manner that consoled her bystanders for whom the spectacle turns into a spiritually enlightening moment: "'O, Eva, tell us what you see! What is it?' said her father. A bright, a glorious smile passed over her face, and she said, brokenly,—'O! love,—joy,—peace!' gave one sigh and passed from death unto life!" (Beecher Stowe 257). The heavenly vision of the beyond that Little Eva grants her bystanders is in the deathbed scene of Cody secularized and thoroughly detached from any divine reference. Nonetheless, the last words as a message from beyond uttered by the "native informant" of death resemble the same idea. Both deathbed scenes framing the documentary – the opening and closing scenes – "console" the bystander corroborating the security found. However, the security found in the escape from the normative biosecurity practices of survival replaces the promise of controllability only seemingly. Awareness and acceptance emphasized in this new security practice do not indicate an acceptance of fate but re-enforce the primary role of medical practice and controllability.

Not without my Doctor

The practice of physician-assisted dying represents a counter-narrative to the dominant biosecurity narrative of survival and to the traditional understanding of medical practice. In fact, some people, such as a counter-protestor interviewed in the documentary claim that Death with Dignity "is not medical practice" (*How to Die* 1:10:10) and a violation of the Hippocratic Oath. But though assisted dying clearly represents a counter-narrative to the biosecurity narrative of medical salvation geared toward survival, the security narrative supporting the practice cannot be divorced from medical practice and the normative power of medicine. Rather, the documentary makes clear that PAD represents yet another facet of biosecurity. It functions as a replacement and a changed version of the original promise, but it is a biosecurity narrative nonetheless.

From obtaining the prescription to the taking of the medication and the final deathbed, every step of the process is accompanied by medicine as the arbiter of security. The security practice of PAD heavily relies on medical authority and represents a medically facilitated death rather than an escape from the normative power of medicine. It is the unchallenged biomedical power that decides the legal availability of this alternative security narrative – the safety net. Since the diagnosis of "six months to live" is the prerequisite for the security practice to be attainable the process of dying has to be literally "named into being" by a doctor. The authoritative voice of medicine is thus comparable to Austinean performative words, which create the reality in the moment the words are uttered. The process of dying can rarely be recognized and experienced without this performative shift. In the case of physician-assisted dying, however, it not only informs the individuals about their security status, and thereby making dying experienceable, this "naming into being" determines the availability of security. The diagnosis represents the prerequisite for accessing the security practice of "dying well"

referring to both, the awareness and the medication that together promise the security in dying.

This reliance on medical diagnosis to instigate a performative turn defining the shift from "sick" to "dying" also becomes obvious in the representative problem of the documentary. Most of the dying individuals in the documentary do not embody the corporeality associated with dying, some do not even necessarily appear sick. Visually and narratively it is thus the representation of diagnosis, symptoms, and reading of CAT scans that define the individuals in the documentary as dying. Since individuals who decide for Death with Dignity have to be of sound mind and have to be capable to self-administer the prepared medication, the dying bodies fail for the larger part of the documentary to represent the corporeality that is culturally expected in dying. Cody, for example, is introduced initially while hiking with two friends laughing and joking about her preparations for dying – she invites her friends to "shop her closet" (0:15:22). Her body is marked by heavy breathing but her positioning as dying relies entirely on the intertwined medical history and final diagnosis of the recurring liver cancer: the authoritative voice of the medical narrative.

Shortly after introducing Cody the documentary starts skipping back to explain why this seemingly healthy woman has decided to take advantage of Death with Dignity. Cody explains how inexplicable pain prompted her to see her doctor, which represents the transition to the medical narrative. It is followed by an interview with her doctor explaining Cody's diagnosis and showing images of her first ultrasound exam. Her illness narrative is represented alternatingly by Cody's voice-over commenting on her bad surgery results, a short section of an interview with her husband quickly followed by more post-surgery images, and the voice-over of the daughter explaining further the long and difficult recovery. Without the knowledge that Cody is dying the narrative would represent the common and familiar structure of illness narratives of fighting an illness. However, Cody cannot leave her temporary "sick role" behind (Parsons) but becomes part of the "remission society" (Frank).[35] The next CAT scan cuts short this illness narrative of fighting disease and reclaiming life: The voice-over of the doctor explains the meaning of the visual image (the scan), which represents the onset of dying. This scene uses the medical and technically facilitated image of cancer to performatively represent dying, or at least its beginning. The image makes (affectively) present the reality of dying, producing it in the very sense of performativity. Since this diagnosis and performative turn obviously preceded the timing of the documentary the moment is recreated visually with the images and the doctor's voice-over emulating the shift of reality for the audience. The doctor's voice is needed to explain the technoscientific image as a representation of dying: she asserts that there are "no options" (*How to Die* 19:30). This performative turning point is crucial and shows how difficult it is to determine the onset of dying.

This central positioning of the doctor, the professionalized and sanctioned authority over life and death, shows that dying requires an authoritative voice to create the perceivable reality of dying. Though such a diagnosis is ambiguous and not always feasible,

35 Arthur Frank defines individuals who are part of the remission society as "effectively well but could never be considered cured" (Frank 163).

it is nonetheless crucial to instigate the change of reality from illness to dying. The documentary reinforces this perfomative turn from sick to dying with an intertitle: "Cody was diagnosed with 6 months or less to live on February 16th. / She plans to take the lethal dose of Seconal on May 25th, Memorial Day" (*How to Die* 23:28). The intertitle not only reiterates the diagnosis as a necessary performative shift but ties the onset of dying to a decision. This decision, however, is not whether to die but how to die and when to die. Thus, the promise of Death with Dignity rests not just on the promise of dignity but of total control. Though a liberating counter-narrative to the biomedical security narrative of survival, it nonetheless relies on the elements of the normative security narrative, namely controllability. The loss of control feared in the prospect of an un-administered death is contrasted by controlled temporality and physicality. Security in dying and dignity is represented as the foreclosure of uncertainty, which is offered by the physician.

The turn from illness to dying is important on a legal, but also on a personal level. Medical diagnoses are crucial for the experience of dying to "institute" the process as well as to define and explain the different phases. The documentary shows that today patients are often unable to "understand" the severity of their condition because the knowledge of the terminal illness does not always coincide with the physical signs of decline that are expected, as sociological studies point out (Kellehear, "On Dying" 389). The ambiguity of Cody's experience of dying shows how important professionalized readings of bodily performances are for the understanding and experience of dying. Accompanied by nature shots and contemplative flute music the audience is informed that Cody has outlived her prognosis. Though this shows that death and dying is not just "created" and defined without referencing a materiality, the representation at the same time indicates the normative experience of dying. At the doctor's office Cody states that, "I am lucky not to be feeling sick" (*How to Die* 47:13) but she is confused because her body does not conform to the imagery of a dying body. She feels as if she is not experiencing dying properly, nor acting like "a person with a terminal illness" (*How to Die* 1:01:32). That she understands her body as failing to represent the risk that it poses to her life emphasizes the importance of the performance of the body "surface" to understand and experience one's security status. Cody asks jokingly: "I am ready to start to decline, and I am not declining. What's the matter?" (*How to Die* 1:02:06). Cody is only able to understand the meaning of her bodily symptoms on the basis of the medical explanations. And she can only time her death on the basis of this medical narrative of decline. Medical estimations are thus not only necessary to be eligible to access PAD but are crucial to facilitating the awareness and acceptance that are core elements for the security practice of dying well.

The inability to fully understand her bodily processes and the absence of symptoms of decline without her doctor's explanation is structurally decisive for the security narrative of dying. Again, it is the other – this time in form of the medical professional– and not the dying self who relates and explains, and thereby determines the meaning of dying. Medical explanations both explain symptoms and provide "the language" to describe and understand the experience. Accordingly, Cody's suffering and increasing pain is described primarily by medical markers, namely pain medication. The doctor explains that "about three weeks ago Cody was on a very minimal amount of pain medication, within the last three weeks she has gone to needing the equivalent of 10 milligram of IV [intravenous] morphine an hour, which is a lot" (*How to Die* 1:26:51). Likewise, Cody de-

tails her suffering by the amount of morphine she needs an hour (by then 75 mg) (*How to Die* 1:35:37). Suffering and pain in dying are thus firmly positioned within a biomedical model.

The importance of biomedicine in the story of dying with PAD is further increased in the narrative construction exemplified by Cody's storyline. The testimony of Cody's dying – the "truth" told by the native informant – represents rather a shared story of patient and doctor than an intimate account by one narrator. Cody's failing body and the onset of the last part of the process of dying is introduced by an intertitle informing the audience about the physical problems and the needed procedures accompanied by slow piano music. The documentary cuts back to the doctor's treatment of the physical symptoms such as the changing of tubes and draining of liquid to alleviate the painful swelling of Cody's stomach due to fluid build-up (*How to Die* 1:15.52). In fact, the doctor takes over the narrative quickly after Cody's introduction (*How to Die* 17:17). Medical language dominates her narrative sequences which represent a guiding and equal element in the story of Cody's dying. Cody's story starts with her first symptoms of pain but it is the doctor's reaction that explains the gravity of the situation: "she [the doctor] called me into her office and then she burst into tears, and she said, 'You have a big mass in your liver'" (ibid.). These shifts in narrative voice between the doctor and Cody emphasize the necessity and predominance of the medical perspective in dying, especially for the practice of PAD. The dying depicted is a shared story told from different points of view, which make clear that the doctor is an important actor in determining and evaluating the process of dying and facilitating security beyond the initial diagnosis.

The representation by the interchanging narrative voices thus do not just dominate the onset of dying but the entire narrative of dying. Most poignantly, before the difficulties of the decision for Death with Dignity within Cody's family are mentioned the documentary shows the doctor's emotional reaction to the diagnosis and her moral dilemma. The doctor's decision to write the prescription stands at the beginning of Cody's storyline as she explains: "It kind of shocked me thinking about it in an intellectual realm … versus I am gonna write a prescription which will end someone's life" (*How to Die* 19:59). Cody's and everyone else's decision for physician-assisted dying is in contrast represented as a foregone conclusion – a decision already made. The conversations, quarrels and negotiations that presumably precede such a decision are only represented temporally following the doctor's explanation in the narrative.

Considering this central positioning of the medical narrative it is not surprising that it is the doctor's narrative perspective that reveals the important turning points of the narrative of dying. She tells Cody that the cancer has returned and she is the one that narrates Cody's decision for Death with Dignity: "She [Cody] said, if this comes back I know there are no good treatment options. I will want that in reserve, the death with dignity law" (*How to Die* 19:50). She announces that "this is the change" once Cody starts to visibly decline (*How to Die* 1:22:00), affirming the onset of "acute" dying, and it is the doctor who announces the moment when Cody decides it is time to end her life (*How to Die* 1:26:55). And finally, it is the doctor's schedule that determines the actual time of taking the medication. Cody's process of dying, and the security narrative for that process, are thus narratively represented as a shared story between Cody and her doctor.

The professionalized reading of the body in dying also marks the decision of the "timing of death" that is so crucial in the modern way of good dying as discussed previously. Cody asserts at the doctor's office: "Actually, the main thing we wanted, is to get a decision tree from here" (*How to Die* 1:23:08). When the doctor explains how life-prolonging measures could get her to Christmas, Cody declines, deciding that she could not do it. The last preparations at the hairdresser are really just the visual and narrative anchor for the doctor's voice-over that dominates the scene. She elaborates on Cody's pain, what her dying without Death with Dignity would look like and finally how she had been asked to attend the deathbed and "made a date for her life to end" (*How to Die* 1:31:04). It is the doctor's voice that introduces the deathbed scene proper starting with the intertitle "Saturday" (*How to Die* 1:31:40). The story is thus not just told by interchanging narrative voices of Cody and her doctor, but it is the doctor's voice that ultimately dominates the narrative determining the timing of death and introducing the deathbed scene – the climax of the achieved security in death. Though the self-reliant autonomous subject is foregrounded in the security narrative promoting physician-assisted dying, the narrative construction and therefore security itself is highly dependent on the other. Furthermore, rather than contradicting the dominant idea of biosecurity in terms of controllability, the narrative emphasizes this foundation of understanding security. The security practice of self-administered death is not just a decision to (let) die but the decision when to die. This controlled and chosen time forestalls the possibility of losing dignity in suffering.

The security narrative of physician-assisted dying, thus, does not simply contradict and resolve the failed biosecurity narrative of survival and life. The promised security recedes and slightly changes, but the core elements of controllability and the understanding of what good life is, remain stable. Furthermore, the source of security remains the same. Security cannot be found "alone" but has to be professionally prescribed and guided. The documentary represents the simultaneous failure and success of biomedical security: "We had the one chance of surgically removing it all and hoping that would be enough for her" (*How to Die* 17:46). The importance of medical knowledge and practice which is highlighted in the documentary, shows that physician-assisted dying cannot be seen simply as "escaping biosecurity" but rather as representing a further facet of the pervasive biomedicalization of life. It shows that the "new" security narrative of dying well represents a displacement of the "original" promise of survival which is substituted with the promise of dignity guaranteed by ultimate controllability.

Making Security: Disease Activism and Affective Legislation

> My dream is that every terminally ill American has access to the choice to die on their own terms with dignity. Please take an active role to make this a reality.
> *Brittany Maynard*

Though *How to Die in Oregon* is rather unique as a documentary and as a representation of PAD, the filmic documentation of dying has become a more common phenomenon,

which is also used by Brittany Maynard quoted in the epigraph. For a brief moment at the end of 2014 she became internationally famous and a heroine for many people around the globe who followed her video posts. She was diagnosed with a terminal form of brain cancer and chose to die on November 1st using her right to die under the Oregon Death with Dignity Act. But that is not what singled her out from all people who opt for the security practice,[36] nor was it the fact that she was a comparatively young woman who died "before her time" as the cultural script would categorize it. What was most important was that Brittany made her process of dying public on the Compassion and Choice website in an attempt to raise awareness for the importance and legitimacy of Death with Dignity. The videos about her decision and process of dying "went viral," producing a publicity for this understanding of security in dying that forced public debate internationally.[37] The circulation of her videos and the encouragement and compassion for the woman's suffering that these generated were so pervasive, that the Vatican felt compelled to intervene and condemn Brittany's decision to end her life before her disease could. Brittany's videos are perceived to have directly influenced the Californian legislation, which was passed as the End of Life Option Act a year after Brittany's death. The president of Compassion and Choice Barbara Coombs Lee even commented in the anniversary video "Brittany Maynard's Legacy": "[The] wind of Brittany's message filled our sails…I don't think anything can stop us now" (Compassion and Choice 5:58). Since Compassion and Choice aired Brittany's videos 15 new bills have been introduced to hearing proceedings (Compassion and Choice News March 10, 2015).

The documentary as well as the video posts epitomize a predominant method of "disease activism" based on testimonials. They are a key element in providing narratives legitimizing the practice as a necessary right. As in the context of breast cancer discussed in the previous chapter, the production of such testimonies is crucial to the Compassion and Choice movement, which calls on individuals – both dying and bereaved – to become storytellers. The documentary echoes this reliance on personal narrative by making the dying the storytellers and authors of their own dying. For Compassion and Choice, the personal stories provide the main vehicles of promoting PAD, which the documentary reflects with Nancy's storyline. The prospect of changing the law to legalize the practice forms her motivation for sharing her husband's story of dying which represents the central practice of her activism. Nancy's and her husband's story are thus not just told to and for the audience of the documentary to represent the threatening horizon of dying without the possibility of PAD, they also emphasize her main role in the movement to legalize Death with Dignity: giving testimony.

The documentary reflects that dying well symbolizes a return to both awareness and acceptance of death as well as to the public nature of dying. And also today the public characteristic of the process of dying can be described as an act of making security,

36 According to the annual report of Death with Dignity by the Oregon Public Health Division 105 individuals have ended their lives taking advantage of physician-assisted dying in 2014. Altogether 859 patients have died using the law since it was enacted in 1995 (1–2).

37 Her first video "A Video for All My Friends" was released in October 2014 by Compassion and Choice has now had over 12 million views.

though for disparate reasons than its 19th century predecessor. Today, the public character of dying does not refer to the deathbed but rather to the documentation and circulation of a way of dying. While the documentary as well as the storytellers of Compassion and Choice are more clearly aimed at activism, video testimonials of dying are remarkably more commonplace. The rise of blogging and social media, and especially v-logging have changed and challenged the narratives of dying by allowing "everyone" to share their own stories. In these representations the act of storytelling often also functions as a form of healing similar to traditional illness narratives.[38] Storytelling is thus one important element of making security on two different levels: On the one hand it is seen as a form of healing, a "pastoral intervention" also reflected in "life review conduct" (Howarth 181, Kellehear, "On Dying" 392). On the other hand, in the documentary, the testimonials are more importantly a form of activism explicitly connected to the legalization of the security practice.

As shown above, the juxtaposition between a "good" and "bad" death establishes dying without Death with Dignity as dehumanizing and unnecessary suffering for the patient as well as for the caregiving family. The only solution offered in Richardson's documentary is the quest for legalizing Death with Dignity in states where it is still banned. In both storylines the narrative forms a climactic development toward the completion of two success stories: Cody's peaceful death thanks to Death with Dignity and Nancy's triumphant delivery of all the necessary signatures to the Washington State Capitol in Olympia. The euphoric "happy end" of the story of activism is further highlighted by the closing scenes of this storyline. A dramatic emphasis in the close up of the women counting the signatures leads up to Nancy's final speech where she elaborates that "My husband … didn't feel that any government or any religious leader had the right to tell him how long he had to suffer" (*How to Die* 49:51). It represents the end of a struggle that places Death with Dignity clearly within the discourse of Civil Rights and the promise of security expressed in the Declaration of Independence. This relation between nation and individual is also summarized by Roger's last words which introduce the documentary: "I thank the wisdom of the voters of the State of Oregon for allowing me the honor of doing myself in of my own volition, to solve my own problems, thank you all" (*How to Die* 3:00).

The narrative connection of dying well and legislative change to make this "right to die" possible represents two crucial elements for the security practice of dying well. It further establishes the documentary itself as a crucial object for the struggle to make security possible. Rather than a controversial discussion of the competing security narratives of dying well, the documentary represents a clear-cut didactic narrative supporting the practice of physician-assisted dying. Though the documentary carefully represents the right to die as a necessary choice that every American should have the right to, other choices and possible practices remain largely absent from the narrative. The representation of palliative care, hospice care and pain management, or end of life directives would complicate the unambiguous security narrative Richardson offers with the dichotomy of

38 Dying V-loggers are usually younger individuals such as Charlotte Eades (16–19) who chronicled her dying from a brain tumor between 2014–16 (Brain Cancer: Dying to Live, Living to Die), the blogger Eva Markvoort (65_RedRoses) in 2010, Miles Levin (18) in 2007, Michelle Lyn Mayer (39) in 2008, to name but a few.

choosing to die well versus a continued struggle for survival. Rather, the documentary represents a call to legalize the practice, representing it as an essential right of American citizens and becomes therefore itself part of the effort of making security. The documentary offers a sympathetic portrayal of the practice of Death with Dignity with an underlying educational agenda of "giving a voice" to what supporters call the quest for the ultimate civil right. It is not a balanced representation of a controversial practice but a carefully composed exposition of the Death with Dignity Act as a necessary and important legislative act. The testimonies of the dying and their claim to authenticity are thus a decisive tool for the ulterior motive of the documentary. Storytelling becomes in the documentary not only a last act of closure, but a last act of activism and of making security.

As the epigraph at the beginning of this section shows, this patient activism is firmly situated in an American rhetoric tradition. In her appeal for support of the Death with Dignity cause Brittany Maynard's call for the right to die well references one of the most famous and widely quoted civil rights speeches, namely Martin Luther King Jr.'s "I have a Dream." She thus puts herself and the support group championing Death with Dignity in a long line of civil rights activists who demand the protection of their rights as American citizens. This protection is not meant as a form of government intervention, however, but rather the opposite. Derek Humphrey, the founder of the Hemlock Society, proclaims in his manifesto "Liberty and Death" that "In a spirit of compassion for all, . . . every competent adult has the incontestable right to humankind's ultimate civil and personal liberty – the right to die in a manner and at a time of their own choosing" (n.p.). The reference to the foundational text of the American nation, the paraphrasing of the Declaration of Independence, is crucial. The claim to civil rights remains a stable – if not staple – element of the security narrative provided. Throughout the documentary Death with Dignity is represented as a right of a person in need of protection, while the prohibition of the practice symbolizes a breach of authority into the privacy of the individual. To establish the meaning of dying the documentary therefore follows the dominant argumentative elements of autonomy and choice, that define the practice, as I have discussed above. The narrative remains in the realm of privacy presenting physician-assisted dying as an individual and personal choice (for security), therefore establishing a link to core American values and identity narratives. It strongly rests on the opposition to government control or intervention in dying as a private individual practice. Furthermore, the narrative references the myths of U.S. American self-reliance – the ability and right to choose and take care of oneself.

This right to die, however, rests on affects, which were already central in the construction of the security narratives in the preceding chapters. The established meaning of dignity or rather its potential loss in the process of dying is based on fear attached to suffering in dying while death "in time" represents hope. It is thus affective attachments that determine the evaluation and understanding of suffering and fear (of losing autonomy and control). As shown in the analysis of *How to Die* it is not a logic argument that proves the inevitable "goodness" of Death with Dignity, or inversely the inevitable inhumanity of pursuing treatment up to the last moment. Rather the right to die is based on a call for compassion with the decision of a person in such a situation. The argument for the possibility and legality of this security practice is therefore based on "affective facts"

(Massumi, "Future Birth"). As such, affects do not only determine the understanding of dying but are productive on a social scale leading to changes in medical practice in a cultural as well as in a legal sense.

Affects therefore determine both the way security in dying is understood, and how the experience itself is perceived, as well as influencing to a large extent the process itself. Medical practices, which govern most deaths in the U.S. today are thus based on both facts and affects. Affects therefore determine the attitude and understanding of dying as well as legislative measures such as the Oregon Death with Dignity Act in 1997. Since the understanding of dying well with PAD is not just a personal attitude but ultimately aiming towards legislative change, the documentary represents an instance of "affective legislation."