

The interval and the instant: Inscribing death and dying

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ABSTRACT

Non-fiction filming involving death and dying has taboo status in terms of what western 1 society can and cannot sanction - the image of dying is not something we should see, or 2 even want to see. As a consequence, there is very little film-making done with the consent 3 and collaboration of the dying person and there are few moving images of natural or 4 good deaths. The documentary film-makers and artists who have navigated this difficult 5 6 ethical territory, engendering a space where dying and death can be given images, have done so by adopting a way of seeing, and being with, the terminally ill person that has 7 8 some confederacy with the practices of the palliative care professional. Drawing upon the writing of Vivian Sobchack and Ernest Becker, as well as Giorgio Agamben's theory 9 of bare life, and particularly Emmanuel Levinas and his concept of alterity, the article 10 concentrates on art and film that turns to face death and dying. Moving through narra-11 tive cinema, observational documentary and artists' film, and examining specific film 12 works by Stan Brakhage, Sophie Calle, Kirby Dick, Allan King and Bill Viola, among 13 others, the complex area between ethics and aesthetics is explored, suggesting that in the 14 15 context of film and death there can be an ethics of aesthetics.

KEYWORDS death and dying palliative care ethics alterity bare life immanence documentary artists' moving image fiction

Death in our culture is among the least expressible and least malleable of subjects available to a film-maker. Vivian Sobchack (2004: 257)

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Introduction

When we think of an artist or documentary film-maker introducing a camera to the last weeks, days and hours of a person's life, and to the moment of their death, our default response tends towards concern for the individual who is dying – we wonder if such an image is appropriate, sensitive and permissible. Has the film-maker obtained consent to be present at such a private time, and, moreover, do I, as the viewer, have permission to witness? I want to suggest that while this response reflects sensible consideration for the needs and situation of someone approaching the end of life, it also reveals aspects of western culture that regard dying and death as that which must be repressed or partitioned. There is no attempt to enunciate what death and dying is, what occurs, what is experienced, where taboo still exists and what society can sanction. My interest lies in this rarely navigated ethical territory, in film and art that, attempts to engender a space where dying and death can be given images, testing the limits set by society.

Narrative cinema tends to work to formulaic portrayals of natural death, which I will 16 briefly address. Observational documentary and artists' film, conversely, can confront 17 the real of death and dying with thicker and more candid descriptions, remaining in 18 the duration of dying where fiction truncates and hastens to exit. However, encoun-19 tering the actuality of dying carries with it profound ethical as well as logistical and 20 aesthetic challenges. By exploring the complex area between ethics and aesthetics in 21 non-fiction film involving death and dying, I hope to suggest that there can be an 22 ethics of aesthetics. I am going to consider how, where and when we look at dying, and 23 this will involve positing particular kinds of looking: the look returned and the non-24 returned look. In doing so I will give close attention to specific films by Stan Brakhage, 25 Sophie Calle, Kirby Dick, Allan King and Bill Viola, among others, all of whom, in 26 different ways, have attempted to inscribe dying and put death and its image back into 27 the public realm. The term 'inscription' is adopted from Vivian Sobchack's important 28 2004 essay 'Inscribing Ethical Space: ten propositions on death, representation and 29 documentary', which gives forensic analysis to the many ethical issues that arise when 30 a film-maker looks at a person who is dying. I am using inscription here to signify the 31 writing of social behaviour and of social space through the making of moving images, 32 and by this I mean to suggest that a certain kind of film-making might write new ethi-33 cal and behavioural spaces not yet fully mapped by society. Such inscriptions are pred-34 icated on the temporary relationship between film-maker (as stranger, as interrupter) 35 and subject. Similarly, the end of life care professional and the patient may foster an 36 uncommon new relationship, one that can involve physical and emotional directness, 37 the carer being witness to events, experiences and expressions that wider society (or, at 38 times, family and friends) do not see, and making representations (medical, corporeal, 39 holistic) of the person cared for and their symptoms. Such points of tentative connec-40 tion between film-making and palliative care are central to the films given attention 41 here. My chief philosophical companion in this respect is Emmanuel Levinas, whose 42 ideas on the face-to-face encounter, alterity and identity as creative production have 43 much to offer contemporary attitudes towards both palliative care and film artworks 44 that involve working with vulnerable others.1 45

Some of the film images scrutinized here depict bodies after death. A number of 46 the works cited portray bodies before death but after personhood has ebbed away, 47 what Giorgio Agamben, in his discussion of the stages of coma, refers to as 'bare life' 48 (1998). For Agamben, bare life is the undecidable state or third principle between the 49 binary of zoe (the biological body) and bios (that body's entry into the political body). 50 Persons kept on life support, in permanent coma, redefine the margins of living and 51 dying. I want to extend Agamben's thinking on bare life, as it applies to coma, into the 52 consideration of nearing the very end of life, and actively dying. What is the status and 53

1. Sarah Cooper, Libby Saxton and Lisa Downing have done important work in the field of film and ethics, looking at both documentary and fiction film, but film studies has yet to scrutinize filmmaking and end of life, and, in general, neglects the activity of film-making as an area of study. Certainly the practice of artists working with moving image and end of life is an area worthy of greater study. See Sarah Cooper (2006), Selfless Cinema? Ethics and French Documentary, Lisa Downing and Libby Saxton (2009), Film and Ethics: Foreclosed Encounters and Emma Wilson (2012), Love, Mortality and the

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agency of dying as bare life, and where it is included in film and art, what are the issues
 of consent that such inclusion provokes?

Given the enduring theoretical links between moving image and death, I will first of all set out some terms that speak to the temporality of end of life and how this informs the mode of address of a camera, and therefore a film. These terms, I hope, will be useful in examining representation, time, duration and the event of the cut in films addressing death and dying.

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The interval and the instant

13 Like adolescence in the 1950s, dying is a new social status, one that is increasingly populated, but it has not been given legitimacy or a sufficient description. Curiously, 14 15 the relatively new social group of the terminally ill is presently constituted by the very 16 adolescents of the 1950s and 1960s who profoundly challenged societal values around sex, drugs, culture and politics as they emerged into adulthood. We are thus entering 17 18 a period of the countercultural death, and with it, potentially the taboo-challenging death, as might be evidenced by the recent artful stage managing of terminal illness by 19 David Bowie and Wilco Johnson, or Clive James's death diary in The Guardian (2016). 20 As qualities of lifestyle improve and with advances in medical care and intervention, 21 we are dying later in life and dying is taking longer, and yet dying remains socially 22 stigmatized and kept apart. 23

We might think of the period of terminal illness, once a diagnosis has been given 24 and finality determined, as a temporal interval, the extended time of the approach of 25 26 death when the terminally ill person commonly withdraws from society, but is also overlooked by a society that regards mortality with anxiety.2 The unease we feel about 27 28 our own inevitable deaths is clearly one of the reasons why we repress and conceal the deaths of others, and why we restrict filmic records. Our being-towards-death exists 29 continually, as a moving towards something that has no clear referent. In Being and 30 31 Time ([1927] 1978), Martin Heidegger asserts that being in the world (dasein) is always a being proximate to and distant from death. Death has no object and no image, it 32 is not a thing, it is not an event in life (as Wittgenstein remarked) but nonetheless 33 it is against me, like a person, as though a foe, a predator. For the person with a life-34 limiting condition or a terminal diagnosis, this anxiety of proximity is fully present: 35 the interval has asserted itself, as a duration. Within this duration, the individual can 36 experience profound physical and perceptual change, and often, a radical alteration in 37 attitude to the world and to others follows. However, the agency such a person has as a 38 creative producer of his or her life is frequently denied them, and they instead encoun-39 ter social exclusion, precisely because there is a reluctance to accompany the dying 40 person into that space and time.³ While medical professionals might wish to protect 41 the privacy and dignity of their patients, their well-intentioned caretaking of terminal 42 illness, may occlude the validity of the dying person's need to speak, and participate 43 in the creation of an image of their dying. The protracted duration of terminal illness, 44 with its profound emotions, transformations and associated phenomena, for the most 45 46 part, lacks adequate expression, and of all the modes of expression available to us as a 47 species, the cinema is foremost in its ability to evoke duration.

Looming on the horizon of this interval (a duration which slows and speeds and changes, its limit not easily foreseeable), there is the actual instant of death. Death is the end of sentience and of signification. Aside from the profound representational problems this induces, there are also cognitive difficulties. There is no clear correlate for death in experience. Only those with religious convictions or openness to the possibility of a spiritual realm believe that we have reports back from death.⁴ For

2. In *The Experience of Dying* (1977), E. Mansell Pattison observes that for perhaps the first time in history, we have many people who are experiencing a new phase of life: the living-dying interval.

 This temporal distension also applies to those witnessing death and dying, in terms of the process of waiting.

4. There is not space here to explore near-death experiences and the phenomena they can produce, the subject of Kate Broome's BBC documentary *The Day I Died* (2002).

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producers of images, death is not only an event of considerable ethical complexity but also one that threatens to de-stabilize language and the imagination, with metaphor and symbolism inexorably rushing in to stand for absent indexes. This instant is not just a challenge to the film-maker-subject encounter. Within the medical and scientific community death is a zone of scientific contestation, and there are even cultural differences in terms of when, exactly, a person is pronounced dead.5 Nonetheless, there are (relatively) clear protocols and ethical guidelines regarding terminal illness and the event of death for doctors, priests, and lawyers, but less so for artists and film-makers, whose exploratory practices have wildly different methodologies as they encounter and contravene established limits. Before discussing examples of such practices, it is important to consider how death in western society remains culturally regulated.

Death and western culture, now and before

Society has banished death. Society no longer observes a pause; the disappearance of an individual no longer affects its continuity. Everything in town goes on as if nobody died anywhere.

Phillipe Aries ([1982] 1991: 560)

In an epochal survey of occidental death practices and rituals, Aries suggests that contemporary disavowal of death begins with the profound shift in attitudes towards dying in the Victorian era, from an event witnessed by the community to one that represents the shameful failure of the social body, a failure that must not be seen. Up until the nineteenth century, death had for generations been a public ceremony, one where people freely entered the private bedchamber of the dying.⁶ As doctors began to formulate concepts of hygiene, crowded bedside vigils waned and death instead became a solitary experience. This, Aries argues, led to a medicalizing of death that dominated the twentieth century and endures today, where the hospital is regarded 31 as the proper place for the failing body. By removing death from sight (and collective experience), it acquired exotic properties and became a taboo subject. Attention moved away from the dying and the dead and the unease they induce, and onto elaborate and commercialized funeral processes and mourning rituals. Metaphor and 35 euphemistic language set in - 'passing on', 'passing over', 'loss', 'chapel of rest' - and 36 death as a natural event in life became foreclosed.

In The Denial of Death ([1973] 2011), Ernest Becker writes that ontological anxiety 38 is a natural state for the human being: the world is terrifying; nature is brutal, and so 39 human behaviour at its most basic is driven by the biological need to control death 40 apprehension.7 Becker proposes that the vital conceit of the human character is to 41 create a God-like personality that makes us feel safe, although in doing so we repress 42 our bodies, so as to 'purchase a soul that time cannot destroy', as Sam Keen writes 43 in the introduction to the book ([1973] 2011: xi). In secular settings it is society that 44 constructs a defensive mechanism with which to offset death apprehension, with cults 45 of subjectivity, individuality and the hero system that bestow lasting worth through 46 achievement and legacy. For Becker, it is not our animal nature or our corporeal 47 bodies that are contemptible (as the Victorians believed); neither does he condemn 48 our innate territorial aggression, but instead, he criticizes contemporary society for its 49 obsessive pursuit of self-esteem and its denial of mortality. 50

When we die, even this event must be a 'good' one, with the idealized notion of 51 the clean, successful death a central concept in the hospice movement (although this 52 has attracted criticism from within palliative care in recent years). The good death 53

Death may not be instantaneous at all, with many now referring to death as a process, one that begins before brain stem inactivity occurs and lasts into decomposition. A person can be declared dead by UK definition but still alive by US doctrine (super locked-in syndrome).

6. Prior to the nineteenth century, it was culturally normal, required even, that parents, children, friends and neighbours be present at the bedside of the dying, and before 1800 there are few painted depictions of deathbed scenes that do not feature children.

This is what Jeff Greenberg et al., taking up Becker's concept, call 'terror management' (1986: 189-212).

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creates an optimistic representation of a person who was neither afraid nor in pain 1 at the point of their death, thus propagating an ideal that may be hard to achieve 2 in reality. This creates unrealistic aspirations that prevent us from reaching a deeper 3 understanding of the phenomenon of dving, and restricts images of natural deaths 4 that are not straightforward or 'good'. Emma Wilson points out in Love, Mortality and 5 the Moving Image that the word palliative has the Latin root meaning 'to cloak' or 'to 6 cover' (2012: 12). If palliative care masks or covers a person's pain, and this, of course, is 7 8 immeasurably valuable, it might also contribute, albeit unintentionally, to the continuing societal concealment of terminal illness.8 Certainly, in the stage of capitalism we 9 find ourselves in, where youth and productivity are the two requirements for inclusion 10 in society, death denial and concealment seem to prevail. However, as John Anthony 11 Tercier writes, this leads to a 'paucity of experience' (2005: 22) of what dying means 12 13 and involves, and also to profound misapprehension and misrepresentation. Until we are brought into contact with dying through our own personal relationships, death 14 remains enigmatic and unfathomable, and our assumptions about death and dying 15 16 are often wildly inaccurate. Certainly, popular culture, particularly cinema, offers a kind of heroic dying, or a 'good' dying, dramatically different from our customary 17 18 lived experience.9

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22 Cinematic death

[Hollywood] suppresses, still, the banality and brutality of bodily decline to promote the sociocultural and positivist fantasies of late capitalist culture. Michele Aaron (2014: 155)

28 People die an awful lot in the movies, although they do not tend to die very differently. Michele Aaron declares that the cinematic language of dying is a language of 29 distortion and displacement, in which death is either out of frame (implied but not 30 31 seen); lyrical rather than prosaic; or simply violent and action driven. If we put violent traumatic screen death to one side (Hollywood's spectacular body count is for another 32 enquiry), dying from natural causes has a particular economy in the cinema: it is effi-33 cient and well timed; people manage to speak their last words - just in time. However, 34 the behaviour of the body as it dies (changes in breathing, lapses in consciousness, 35 36 the experience of pain) is rarely seen in narrative dramatic scenes. Instead, the dying person is weak but presentable. Think of Ed Harris's character Richard in The Hours 37 (Stephen Daldry, 2002), or Joseph-Gordon Levitt in the more recent 50/50 (Jonathan 38 Levine, 2011).10 After a death has occurred, the dead body seems outwardly asleep, 39 only paler and more still. This approach may be due to do the inherently un-cinematic 40 nature of commonplace dying, but it is also because Hollywood is less concerned with 41 the phenomena of everyday death (which is minute and inscrutable) and more with 42 the value of death as it defines the narrative of a life, either of the deceased or the 43 bereaved. 44

Within the lexicon Aaron sets out, dying has dominant motifs including self-45 46 sacrifice and saintliness, triumph and redemption, stoicism and beauty. Aaron devel-47 ops her argument by stating that such a grammar predetermining images of death in 48 popular cinema is inherently necropolitical – that is, reflecting the fantasy of a sovereign power exerted over death in the popular imaginary. As Achille Mbembe writes 49 in 'Necropolitics', 'to exercise sovereignty is to exercise control over mortality and to 50 51 define life as the deployment and manifestation of power' (2003: 12). This tendency chimes with, but also amplifies the rhetoric of, the good death; in other words, 52 death is orderly, pain free and spiritually resolved. We might think of Imitation of Life 53

8. In fact, pain control is the mainstay of palliative care, and the efficacy of the care professional is thrown into crisis if the patient refuses medication for pain management. There are few non-fiction films that record a person experiencing pain.

 Non-fiction films focusing on end of life are uncommon.
 There are few factual images of natural or good deaths, or candid articulations of the processes of dying and grieving.

10. John Patterson's recent article in *The Guardian*, 'How Hollywood has learned to embrace the realities of death in film' (June 2015), tentatively suggests that mainstream cinema may be slowly changing its aesthetics.

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(Douglas Sirk, 1959), or *Philadelphia* (Jonathan Demme, 1993), where the death of a moral character produces realization and growth in those around them. Distinctive among screen deaths is the apparent wellness of the character dying, and, if they are classed as righteous characters, they remain attractive in their death. The audience is granted what Aaron phrases as the 'well gaze' (2014: 169); we are not forced to experience discomfort at the physical frailty or explicit decline of the character we witness suffering and dying. There are some rare exceptions in dramatic cinema. Michael Haneke's *Amour* (2011) gives a harrowingly detailed account of the physical reality of dementia, a condition increasingly a part of terminal illness. Maurice Pialat's *La Guele Ouverte/The Mouth Agape* (1974) holds on the body of central character Monique as she dies from cancer, a stark and unsentimental image that describes aggravated breathing and terminal restlessness as well as the agony of witnessing someone in pain and waiting for them to die.ⁿ Pialat's film strays into the territory of the more physically realistic death, yet for the overwhelming majority of film narratives featuring end of life, death is composed, concise and cathartic.

Documentary and dying

... as the film-maker watches the dying, we watch the film-maker watching and judge the nature and quality of his or her interest.

Vivian Sobchack (2004: 243)

If narrative cinema offers false or misleading representations of death and occludes 25 the reality of dying, the documentary confronts this reality head on. However, end 26 of life and the instant of death remain difficult to capture owing to a range of ethical 27 and practical factors. There are rightly concerns about the intrusive nature of filming 28 at this point in a person's life, and their capacity for consent. Given its taboo status, 29 and inherent ethical sensitivity, the documentary film-maker must find appropriate 30 methods - social and also aesthetic - for visually confronting death and dying if the 31 representation is to be perceived as morally justifiable in its gaze at what is normatively 32 regarded as forbidden. News media (and now social media) has a fixation on acciden-33 tal death and violent death, but when foreseeable death, occurring as a result of illness 34 is represented in non-fiction terms, its image insists upon ethical justification. The 35 viewer must be assured of their right to see and know, because a visual taboo has been 36 violated, and typically, it is an invitation extended to the film-maker by the subject that 37 gives the viewer permission to witness. 38

Sobchack's essay 'Inscribing Ethical Space: ten propositions on death, representa-39 tion and documentary' (2004) takes us through different ways of looking, with incre-40 mental levels of moral accountability. First is the accidental gaze, a mode of looking 41 and recording that, owing to its unpreparedness, is least ethically questionable (the 42 Abraham Zapruder S8mm footage of JFK's assassination, for example). Sobchack goes 43 on to define the endangered gaze, typified by embedded journalism, where the ethics 44 of filming is seen in the context of the unpredictability and jeopardy of recording 45 conditions. Then there is the professional gaze - for example the look of the medical 46 expert - a manner of looking associated with institutional legitimacy. Finally, there 47 is arguably the most charged gaze, the human stare, which can be aligned with the 48 long lens, long take of observational documentary. Since its inception, the documen-49 tary has debated what a truthful and an ethical camera attitude to the world might 50 be, and this was (and still is) played out on the level of shot fixity and duration. The 51 long take filmed from a respectful distance is the mainstay of direct cinema, adopted 52 by those who regarded proximity to their subjects as invasive and too intervention-53 al. However, when it comes to end of life subject matter, the very temporality of a

11. The title refers to the open mouth position that often follows death. Critic Miguel Marías has praised the film, and commented that 'the film shows without the slightest trace of sublimation, self-pity or sentimentality what it really is to stand in hopeless, powerless watch for hours, days or even months, feeling inadequate and useless while tiredly sitting near a bedside or restlessly walking up and down, aimlessly, like a caged tiger around the house, waiting for the once and still (or perhaps again) loved one to die. This figure is probably in pain, or suffering from some sort of physical or psychic decay, and is unable to speak fluently or even to breathe'

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(2006: online).

natural death is threatening to the subject and also to the viewer, because the prolonged
duration of dying allows time and space for objectification, or what Sobchack calls the
'ill-mannered stare' (2004: 243), produced by the detached attitude of the camera and
the length of the shot. I will now turn my attention to this human stare as it manifests in documentaries concerned with the terminally ill, and consider how it can look
differently.

An invitation to observe usually stems from pre-existing personal or familial 7 8 relationships, where the film-maker depicts the gradual death of a parent, sibling or partner.¹² For example, in Silverlake Life: the View from Here (Peter Friedman and Tom 9 Joslin, 1993), Joslin, within the framework of a relationship, was invited by the dying 10 subject to observe the process and event of an HIV/Aids related death. The making of 11 the film took place in the context of the taboo-challenging US gay community of the 12 13 1980s and early 1990s, a time when new ways of construing which voices could be heard and how they might speak were being configured. Dying, in this instance, is stared at 14 15 humanely, and the act of looking and filming is sanctioned, in the manner Philippe 16 Aries describes as 'a ritual organized by the dying person himself', who presides over it and knows its 'protocol' (Aries quoted in Sobchack 2004: 11).13 However, even with 17 18 a trusted custodian of the subject (and therefore of the image) present, the anticipatory gaze that waits for and records a known death is deeply problematic, and so 19 film-makers have sought to gain consent not only by invitation but also through more 20 complex collaborations. Kirby Dick's documentary Sick, the Life and Death of Bob 21 Flanagan Super Masochist (1997) closely follows performance artist Flanagan as his 22 cystic fibrosis becomes chronic and then terminal. Flanagan takes ownership of the 23 film, treating it as a stage where he can regain control over a body ravaged by illness.14 24 The film took a long time to make, during which the sensibilities of the performance 25 26 artist and the film-maker cohered and a friendship of sorts was fostered.¹⁵ Flanagan is a practising sadomasochist, and the film offers a candid encounter with his body. On 27 28 camera, his body is laid out, suspended, slapped, penetrated, his genitals mutilated by his partner Sheree Rose, inviting us to acknowledge that the body is always decaying 29 30 and dying. In one pivotal exchange, perhaps referencing the bloodletting in many of 31 Flanagan's own solo performances, Dick suggests to Flanagan that biographers are by 32 definition vampires. Flanagan replies by granting his chronicler the status of collaborator, but then counters with, 'maybe you're more of a vulture, waiting for me to cough 33 and kick off'. The film becomes a discourse on consent, permission and submission, 34 played out, literally, in Flanagan's art, with his tissue (we are shown containers filled 35 36 with fluid drained from his lungs). His worsening condition means that Flanagan can no longer submit to his mistress Sheree, and this makes for uncomfortable viewing. 37 The desire Sheree expresses for her partner to continue to participate in their long-38 established consensual masochistic exchanges, even though he is mentally and physi-39 cally unable, forces the viewer to question not only the ethics of the kind of control 40 she exerts over her partner (and the next-of-kin role in general). It also indicates 41 that no matter how declared consent is, any film of this kind runs the risk of coerc-42 ing its subject into appearing on screen in spite of their current capabilities. In these 43 moments we are not only witness to Flanagan's pain, resilience and vulnerability, but 44 we may also appraise Dick's presence and the disposition of his camera in relation to 45 46 Sheree's frank and unorthodox treatment of her partner.

Sick does not shy away from presenting distressing phenomena as they emerge. At one point in the intensive care unit Flanagan removes his ventilator and expresses surprise at the acute physical sensation he is experiencing, incredulously repeating, 'I don't understand it, this is the stupidest thing, it's the stupidest thing'. After a longer than predicted life managing a life-limiting condition, Flanagan realizes that the sensation he is experiencing means that the event of dying has finally begun. Of course, this is what we know will happen and what we have waited for, and yet we have grown so accustomed to how effectively Flanagan manages his pain and pushes 12. This familial legitimacy governs many legal and social processes in our culture but it can be problematic. It is surprising how easy it is for the terms of a legal will to be contested and changed, and how often the funerary wishes of the dying person are superseded by the choices of the next of kin. In fact, the next of kin have considerable authority in the affairs of the dying and deceased.

13. Similarly, Stuart Marshall's diary and activist films *Bright Eyes* (1984) and *Over our Dead Bodies* (1991) broke ground in finding new representational tools for dealing with journeys towards death.

14. As a child, Flanagan was told he would in all certainty not live to adulthood.

15. In the memorable opening sequence, Flanagan attacks the Disneyfication of the body – which must never be imperfect or unwell – by changing the lyrics of *Supercalifragilisticexpialidocious*, to 'Um diddle diddlediddle, I'm Gonna die. Um diddle diddlediddle, I'm Gonna die'.

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the limits of his body into excess that to realize death is an excess Flanagan's art cannot assimilate is both sad and unsettling. The moment of death is not given, and instead 2 we see Sheree's photographic sequence, taken soon after Bob's death: the bed; the 3 room; Flanagan's body and face in close-up, inanimacy.16

Another example of a documentary approach to end-of-life is Dying at Grace (Allan 5 King, 2003), set in the palliative care unit of a private Toronto hospital and featur-6 ing five terminally ill patients who share the last days of their lives, and their deaths 7 with King and his small film crew. The film adopts a waveform action of character 8 introduction and familiarization, spending time with Carmela, Joyce, Eda, Richard 9 and Lloyd in their hospital rooms, as they each, in turn, pass through phases of defi-10 ance (trips out of the hospital) and resignation, deterioration, then death and its after 11 effects. Interspersed with these intensely private experiences are nurse briefings, night 12 reports and dictaphone recordings, which act as narration and character exposition. 13 Such exchanges are candid but also euphemistic, with cancer always delicately coded 14 as 'C' (of the bladder, for example). King does not conduct interviews nor declare 15 his presence and is never addressed by his contributors. Instead, intimate face-to-face 16 conversations between patients and their chaplains, psychiatrists, counsellors and 17 nurses provide the opportunity for discourse on mortality, legacy, family, last wishes 18 and faith, many of them carrying a Christian subtext.¹⁷ In these conversations, we as 19 viewers know the outcome, we know that Eda, who is hoping her next CAT scan will 20 offer a reprieve, will soon die, and this puts us in a position of both compassion and 21 pre-eminence. King, in a 2006 TVO interview, expands upon his 'actuality drama' 22 methodology, commenting that his subjects know the camera is there and want to be 23 able to use it to express themselves, in the hope that other people may benefit. 24

The film is outwardly uncompromising in its absence of rhetorical devices, although 25 the tremulous looks between Joyce and roommate Carmela are clearly afforded by the 26 edit, as are cutaways suggesting Carmela silently listens to those nearby comment-27 ing on her situation, and the shot of Joyce's death, her expressionless eyes and open 28 mouth briefly held in the frame, before cutting to staff singing Christmas carols. These 29 cinematic devices are what King would qualify as drama evinced from everyday life. 30 The style achieved in Dying at Grace, as Michele Aaron notes, is confrontational but 31 not frontal or solipsistic, neither is it heroic (2014: 161). We are witness to the move-32 ments and activities of the hospital ward and its environs: carers and intimates strok-33 ing fingers, hands and faces, the automatic body and its pentameter of drawing breath 34 at regular intervals, and, accompanying this biological phasing, the insistent drone 35 and sporadic bleeps of hospital monitoring machinery. There is the stark sense of how 36 society puts the dying together with the dying. 37

The inertia brought about by late stage terminal illness, along with the reduc-38 tion in communication we see Joyce and Carmela experience caused in part by 39 morphine and other medical treatments, means that recording end of life predomi-40 nantly involves bedside filming of the silent face in close-up, and this is exemplified 41 by Dying at Grace. At this point I would like to consider such an image of the face in 42 the context of Emmanuel Levinas and his work on the ethical and caring encounter 43 between human subjects. For Levinas, the face of the other is an external question, 44 an invitation to which we must respond. The face is the producer of our subjectivity 45 because we become subjects, and therefore ethical entities, when put into relation with 46 other subjects. In Levinas's concept of alterity, all human faces impact us as affective 47 moments or, what he calls 'interruptions', brought about by a look, a glance or a linger-48 ing gaze ([1961] 1999). The human face is first affective, and therefore open, before it is 49 meaningful or interpretable. 50

The close-up of the face is central to our understanding of cinema, none more so 51 than the documentary, still dominated by the face of the interviewee giving testimony. 52 Comparisons can be drawn between the face-to-face encounters film-makers and 53

16. A similar photographic sequence can be seen when one of the subjects of the Australian documentary Tender (2013) dies. Artist film-maker Lynette Wallworth opts to portray the body after death using still photography, in an aesthetic shift in register clearly considered as a mark of sensitivity, but also of distance. Photography carries with it traditions of practice. It is more socially acceptable to photograph a person who has died than to produce a video camera in that scenario, although we are in a curious moment culturally, given the ubiquity of still

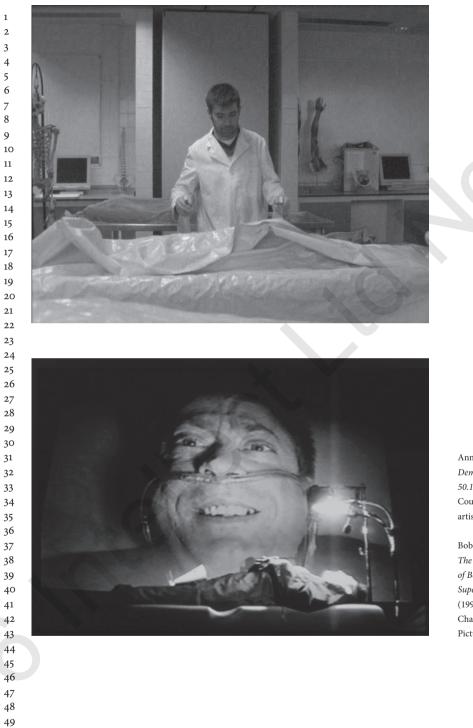
17. Toronto Grace is a Salvation Army Health Centre.

images we now produce.

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The interval and the instant



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Anna Lucas's Demonstration 50.15 (2009) Courtesy of the artist. ۲

Bob Flanagan Sick, The Life and Death of Bob Flanagan Supermasochist (1997). Courtesy of Chain Camera Pictures.

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subjects experience and those of care professional and patient. The hospital and hospice is where we are approached by doctors who treat us, nurses who lean in, enter our field of vision, make contact and attend to us. In the context of death and dying, the role of both film-maker and end-of-life nurse is to some extent that of newcomer/ stranger, interrupter, intervener, someone who does not look away, someone who moves and acts in response to the question of the face of the other.¹⁸

Levinas suggests that ethics is an optics, not only a way of seeing but a way of 7 seeing seeing ([1961] 1999: 78). The presence of the face looking at us creates a crack 8 or breach in the frontality of the things that appear in our visual field. This is why the 9 returned look of the subject is given so much attention in ethnographic cinema, as an 10 event of empowerment, an assertive declaration of presence and cognisance of active 11 participation. It is the returned look of the subject towards the look of the film-maker 12 that Sobchack identifies as a mechanism for denying ghoulishness and morbidity. She 13 writes that 'cold voyeurism is belied by the dying subject's openness to the probity 14 of the gaze, by a collaboration with its interest, by a frequent address to the gazer 15 that inscribes the off-screen presence and intimate acceptance of the film-maker' 16 (Sobchack 2004: 254).¹⁹ Perhaps the most extraordinary aspect of *Dving at Grace* is the 17 manner in which King's hand-held camera, neither intrusively close nor indifferently 18 distant, is unafraid to look at subjects when they are unable to look back, for example, 19 Carmela blankly staring, or Joyce sitting rigidly upright in her bed, her eyes rolled 20 back, 'somewhere else', to use her words. The question presented by the face in these 21 instances is inexorable and unanswerable: where is the person, what has happened 22 to them, where is their interiority and subjectivity? Michelle Aaron suggests that far 23 from ethically compromising the person filmed, King offers a model for a way of look-24 ing not fully figured in Sobchack's classification. This is a space for a further gaze, what 25 Aaron terms the 'long stare at raw life' (2014: 174), which offers 'the potency and awe of 26 exposure' (2014: 175).20 Aaron suggests there may be limitations to an ethics confirmed 27 through consent-as-reciprocity and the relay of looks, as Sobchack sets out, and seeks 28 instead an image whose truth and ethical urgency is located in the dominion of art. 29

Dying at Grace offers a mode of looking that suggests we can go further in propos-30 ing new ethical ways of seeing. Both King's film and Sick demonstrate that documen-31 taries stage the conflicts and contradictions of their making as well as form representa-32 tions, and that, in Sobchack's words, 'documentary space is constituted and inscribed 33 as ethical space: it stands as the objectively visible evidence of subjective visual respon-34 siveness and responsibility toward a world shared with other human subjects' (2004: 35 248).²¹ Nevertheless, questions arise about this ethical space and encounter, where 36 responsibility towards the other may be misguided, or assumed on behalf of the other 37 (gatekeeping), and where respectful distance and restraint might, conversely, deny the 38 subject an image, a creative production, and inclusion in art. Does this ethical space 39 have different rules and boundaries when navigated by artists? 40

Death and artists' moving image

A life is everywhere [...]: an immanent life carrying with it the events and singularities that are merely actualized in subjects and objects.

Gilles Deleuze (2005: 29)

Both Bill Viola and Sophie Calle have included the moment of their mothers' deaths50in their work. Calle's installation Pas Pu Saisir La Mort/Couldn't Catch Death (2007)51spans two white cube spaces. One room features an oil painting of Calle's mother52Monique Sindler. The adjacent room has an eleven-minute looped sequence that53

18. Curiously, in many iterations of non-fiction films featuring end of life, medical and nursing care vacates the frame set out by film-making, with nurses and doctors (and family members) sometimes less willing to be filmed than patients, the consequence of which is that films can tend to produce images of isolation in hospices and hospitals.

19. James Elkins describes how some images cause vision to go out of control; our eyes no longer obey our conscious wishes, the face at times posing the threat rather than the liberation of otherness. Elkins invokes Georges Bataille when he writes that 'some things can never be clearly seen, no matter how much we may want to see them: the sun will blind us (or so it seems), and it may not be possible to see the moment of death' (Elkins [1996] 1999: 12).

20. Aaron may well be paraphrasing King himself, who in the aforementioned TVO interview states that filming *Dying at Grace* 'was about being in awe, of what a human being is.'

21. See also *Dying* (Michael Roemer, 1976); *Near Death* (Frederick Wiseman, 1989); *Griefwalker* (Tim Wilson, 2008) and the recently broadcast *How to Die: Simon's Choice* (Rowan Deacon, 2016). 41

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shows, in real time, the last moments of Monique's life. Monique is never conscious in 1 this duration, and the only movement is the recurring attention Calle and a palliative 2 nurse, partially entering the frame, give to her mother's pulse, checking to see if she has 3 died. Calle recorded some 70 or 80 hours of video at her mother's home during this 4 bedside vigil (the bedroom once again becoming a space for public ceremony) and has 5 described her fear of not being present when her mother passed away: 'I wanted to be 6 there, to hear the last word', Calle explained to Blouin ARTINFO magazine, 'I didn't 7 8 know if she would have something to tell me at the last minute' (quoted 2013).²² Calle hoped to capture Monique's last moments of life and the first moment of death but 9 found that although death can be medically verified, in perception it is very difficult to 10 determine the point at which it takes place. 11

Although by the time of filming Monique is not conscious and has no capacity to 12 13 signal approval of filming, the familial relationship suggests consent, and Calle has said that when she first introduced the camera to the room, her mother's response 14 15 was, 'at last', which Calle inferred as permission. The camera came to be a companion 16 of sorts, with Monique often speaking to it even when Calle was not in the room. The composition, with Monique lying horizontal in bed and framed against the bedroom 17 window, does not change, and the image has a video diary quality familiar from the 18 artist's earlier work (Double Blind, aka No Sex last Night [1992], for example). At the 19 point of recording, there is no explicit sense of Calle aestheticizing her mother. For 20 an artist who has always blurred the boundary between art and life, and made her 21 personal relationships figure heavily in her work, Calle was not likely to delimit the 22 aesthetic and conceptual possibilities of such a lived event, and yet her camera is 23 restrained. The artist has referred to the profound difficulties she faced when it came 24 to editing the material she recorded of the moment her mother died, particularly in 25 26 terms of when and why to introduce a cut in the sequence (2013). Appropriateness and the danger of denigration by the onlooker are not only powerful factors at a deathbed, 27 28 but the respectful handling of the edited image is also important: the decisions about which image will follow and which will precede the moment of death, or, in the case of 29 Pas Pu Saisir La Mort, how long is an appropriate time to hold on Monique before the 30 one edit re-sets the loop and the process of dying starts again. Any edit structures and 31 re-structures events, and here reduces the shock of the death image.²³ Death's violent 32 incommensurability is diminished by montage. 33

Sobchack writes that death is a moment of unspeakable transformation, one that 34 confounds all codes, because death is always in excess of representation. Not only 35 does the body die, but language also fails us and expires around this moment. Death 36 is unrepresentable, even in nonfiction film events such as Monique's death, where the 37 camera can only show us the exteriority of life ending. If death has a sign then it is the 38 sign that signals the absence of a sign, or the sign that signifies the end of all signs, 39 the end of representation. Birth, conversely, is the sign to begin all signs, and in Bill 40 Viola's Nantes Triptych (1992) both death and birth are on display.24 Viola's installation 41 speaks to metaphysical and spiritual ideas of birth, death and re-birth, and incorpo-42 rates bedside footage of Wynne Lee Viola, the artist's mother as she lay dying. For 43 Viola birth and death 'are mysteries in the truest sense of the word, not meant to be 44 solved, but experienced and inhabited. This is the source of their knowledge' (1995: 45 46 251). Like Sobchack, Viola has observed that in the context of the scientific discourses 47 dominating western culture, death is merely a technical process, one that no longer 48 commands our interest emotionally or spiritually (1995: 273).

49 Viola's triptych runs as a 30-minute loop across giant panels, the left screen 50 depicting a nameless woman giving birth in real time to an anonymous child, the 51 central screen showing the artist submerged under water, wrestling with clothing in 52 slow motion, and the right screen the 'passing' of Wynne Lee, who was seen prior 53 to her illness in Viola's earlier single-channel work *The Passing* (1987).³⁵ Wynne Lee 22. Monique Sindler's last word was '*Souci*' (uttered in the phrase 'Don't worry').

23. The sanctity of the person who is dying and the attitude works of art take towards them is further problematized by the commercial salability of any artwork. Calle subsequently showed the installation in what she termed a non-commercial exhibition space, a church on the Upper East Side in New York. The work was also included in the artist's 2009 Whitechapel Gallery retrospective. Also of note is the strict control Calle exerts over the work, with no still images from the installation permitted for publication. Both Viola and Calle work in the gallery, where viewing space conditions can be controlled and the sensitive image protected from errant dissemination

24. It is interesting to note that still and moving images of birth, particularly vivid corporeal images of C-sections, have attained social acceptance and normalcy when they would have been viewed as excessive a generation or two ago.

25. In *The Passing*, Viola's mother appears as an active, healthy and willing participant in the process of making.

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approaches death in the more clinical setting of a hospital rather than the domestic 1 intimacy of the bedroom. She is in a coma, breathing at regular intervals; there is 2 little or no sense of her identity and certainly no indication that she is cognisant of 3 being filmed. We scrutinize Viola's third panel for signs of Wynne Lee's life and for signs of her lifelessness, just as Calle and the attendant nurse repeatedly (and in the case of the loop, endlessly) check for Monique's pulse. This scrutiny is not merely because we want to discover whether the moment of death has an image (did I see it?) but is also motivated by the desire to observe 'a life' as it may be visible, in all of our bodies

For Giorgio Agamben the condition of coma is living what he calls 'bare life' (1998). Bare life is the undecidable, oscillating state between the two most basic categories of western biopolitics: Man and animal. Agamben critiques and dismantles these categories, suggesting that the first category, Man, has been erroneously opposed to other living things and therefore we cannot experience and express creatureliness. This false separation from other creatures is most apparent, Agamben observes, at the very end of life. The coma represents a crisis to sovereign dominion because it is a border that cannot easily be mapped and delimited. It is also a vulnerability that can create an opening in our popular discourse about the body and dying.

Agamben discusses the case of Karen Quinlan who was pronounced dead and so 19 the hospital was instructed to switch off her life support machine. However, Quin-20 lan then reverted to breathing independently, leaving her in a liminal zone beyond 21 the definition and power of sovereign law.²⁶ He attempts to reconcile this example of 22 bare life (coma) - the zone of indetermination between life and death - with the bare 23 life of the bandit who operates outside of the law. Agamben asks how is this interval 24 between life and death controlled and contested?27 We might also extend Agamben's 25 concept of bare life to periods within terminal illness when personhood is profoundly 26 compromised. This returns us to the issues of capacity and consent when filming takes 27 place once communication has ceased and when life is ending (and has ended), issues 28 seemingly assuaged by Viola and Calle's kinship with their subjects. In this respect, my 29 interest is in line with what Gilles Deleuze (2005) speaks of as the ontological essence 30 of 'a life', as it is lost and regained, as it becomes, momentarily, outside of the strictures 31 of identity and society. Deleuze's notion of an 'immanent life' is not an image of a body, 32 but a body as image, free to express forces, affective rather than representative.²⁸ So, 33 from bare life and creatureliness to 'a life', we have on the one hand caution and care 34 prompted by privacy, capacity and consent, but on the other hand, life as it may be 35 lived, in dying, as an emergent situation, a creative production, an experiment. This 36 is the contentious and arguably lawless (to invoke Agamben) area inhabited by artists 37 and film-makers determined that aesthetics challenge our ethical assumptions and 38 expand our ethical encounters. 39

Ethics and aesthetics

Michele Aaron lists the problematic terms of address and modes of signification 45 film-makers can fall foul of when their subject matter is death and dying, among 46 them metaphor and symbolism, and the reduction of the dying person to a spiritual 47 totem, projecting onto them metaphysical ideas of transcendence. We might think of 48 recourse to abstraction as a form of syntactical death, and the pull of symbolism typi-49 fied by Viola's more recent 'angels' (Five Angels for the Millennium, 2001) as extremely 50 hard to resist. The criticism often levelled at Viola, of deification, is also redolent of 51 Hollywood's transcendent narratives of dying in which a life is reduced or canonized, 52 sentimentalized and sanitized. 53

26. In Le Coma Dépassé (1959), Pierre Mollaret and Maurice Goulon provide a structure of increments of unconsciousness. 1. Classical coma; 2. Alert coma: 3. Carus coma and 4. Coma Dépassé, which is the total abolition of relational life and the total abolition of vegetative life functions.

27. Darshak Sanghavi's fascinating article, 'When Does Death Start?' (New York Times, 2009) gives a vivid account of such situations

28. In his last publication, Immanence, A Life (2005), Gilles Deleuze refers to a passage from Charles Dickens's Our Mutual Friend (1864-1865), where the flame of life in the figure of a dying man, a rogue, must be kept burning by the gentry who pass by; it is suddenly their responsibility, but once saved, the personality associated with the life is of no consequence once again.

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The difficulty of appropriate form and what new syntax is permissible are also acute 1 at the level of shot and composition. The steady smooth camera indicates a certain 2 stateliness as well as a permission to be present (there is no hesitancy or unrest in the 3 camera attitude) and yet an overtly graceful shot, such as may be achieved with a dolly 4 on a camera track or Steadicam, might also suggest aesthetic objectification, or even a 5 callous preoccupation with production values, which could translate as a disregard for 6 the subject. Similarly, the use of a considered pan or tilt onto, from, or across a subject 7 8 explicitly aestheticizes their image at a time when such a depiction may appear inappropriate. Both Calle and Viola adopt the strategy of looping video sequences enabled 9 by the gallery context, and we might go so far as to regard the loop, formally, as speak-10 ing to the inevitability and incomprehensibility of death. The loop is anti-narrative 11 and, in contrast to the cinema and broadcast, it is anti-commodity in that it cannot be 12 13 resolved to a scheduled viewing. It will not end. The loop is a simple but devastating violation of our habit of managing the world in terms of progressions and resolutions. 14 15 A loop leaves us with the disposition of looking for the same in the different – we 16 hope not to literally see the same. In its repetition we are the difference; we change, and the loop enacts a riposte to death suggested by a number of religions, that death 17 18 becomes life in a returning cycle. However, this runs the risk of reincarnating and thereby immortalizing the image, and denying the experience of death as finality. 19

If certain kinds of images reduce death and infantilize (to use Aaron's term) the 20 dying, and if, in turn, well-meaning ethical stances can, on occasion, run the risk of 21 preventing the dying (and the deceased) from the sort of direct, intimate and candid 22 images regularly afforded members of society who do not have a terminal illness, what 23 new aesthetic enunciations are possible? Anat Pick, in her work on the non-human 24 subject, calls for the attentive gaze: this is not a conventional type of looking; it does 25 not operate within the circuit of the returned look, nor is it the gaze that interprets 26 or translates and makes sense, but it is the animal gaze, one that is partially glazed, as 27 28 though seeing but not looking, and reflects our inherent creatureliness (Pick's term, adapted from Lawrence Langer, is 'creaturely poetics'). Pick writes that 'the attentive 29 gaze cannot help being "innocent" to the extent that it sees while remaining unattached 30 31 to (uninvested in) its object' (2011: 160). In the context of death and dying, such a way of seeing would involve a haptic contact with the body as a non-signifying bare life. 32

Stan Brakhage's The Act of Seeing With One's Own Eyes (1971) represents the corpo-33 reality of the autopsy, in forensic, visceral detail.²⁹ Part of the film-maker's Pittsburgh 34 trilogy,³⁰ the film was shot during an evening spent in the Pittsburgh city morgue. 35 Although shot on 16mm, Brakhage eschews his established practice of materially 36 working with celluloid, opting instead for an image that is uncompromising in its 37 directness. Rather than intervening in the cinematographic act, the film locates all 38 tactile relations in the bodies it surveys - not so much camera-less as camera-full. 39 Fred Camper writes of the film that 'the stripped-down filming style (silent thus free 40 of all voice-over typical in documentaries) enables the viewer to form their own inter-41 pretations and judgements' (2003: online). Brakhage's camera is hand-held, urgent, 42 penetrative and unflinching. Several cadavers, their identities undisclosed, are set out 43 on mortuary slabs and subjected to the invasive process of examination and dissec-44 tion by both pathologists and film-maker. Torsos are slit open, craniums cut into and 45 46 internal organs revealed. In one challenging section, the face of an unidentified subject 47 is cut free of the skull, peeled back and turned inside out. This is the absolute inver-48 sion of cinema as ideological apparatus, where suture stitches the viewing subject into the discourse of the film, disguising the film transaction, its assemblage, delimit-49 ing the frame, the cut, so as to enable disembodied identification. The Act of Seeing 50 51 With One's Own Eyes gives a form of graphic auto-identificatory embodiment to the viewer. Camper has described Brakhage as the 'documentarian of subjectivity' whose 52 aim is always to 'sensitize each viewer to his own subjectivity' ([2003] 2010: online). 53

29. The etymology of words and terms in popular usage in the context of death and dying seems germane. Brakhage's title derives from the literal translation of the term autopsy, from the Greek word *autoptēs* or eyewitness, derived from *autos* 'self' and *optos* 'seen'.

30. The Pittsburgh trilogy is a trio of documentary films Brakhage made about the city's various institutions in 1971; the other two are *Eyes*, about the city police, and *Deus Ex*, filmed in a hospital.

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However, when we watch Brakhage's film, we are stripped further than this; we are 1 only interiorities, only bodies. This is a vertiginous feeling. Where it is the image that 2 loops in Viola and Calle's works, here it is one's own body that turns in on itself; turns 3 itself inside out. More than anything, the film forces us to look and not stop looking.

Anna Lucas's Demonstration 50.15 (2009) similarly focuses on those who attend 5 to the deceased person between death and disposal, examining mortuary research 6 laboratories and technical processes surrounding the body. Lucas's film, in many 7 ways a striking reply to Brakhage, is shot at Oxford University's Anatomy and Genet-8 ics Laboratory, and follows the repetitive movements of a mortuary technician as he 9 embalms and prepares bodies for medical students. Filming took place under the 10 hyper-strict restrictions set by the university ethics committee and the 2004 Human 11 Tissue Act, which stipulates that no part of a human body can be sold, disseminated, 12 or filmed.³¹ Whenever a part of a cadaver enters the frame of *Demonstration* 50.15, 13 its image has been masked in post-production. As well as a clinical observation of a 14 clinical setting, the work becomes a thesis on our desire to see what has been forbid-15 den. In her essay, Sobchack argues that the paucity of factual images of natural deaths, 16 coupled with a lack of personal encounter with end of life, means that death has come 17 to be understood predominantly as a technical and medicalized phenomenon of the 18 body, rather than a subjectively lived-body experience. The transformation of being 19 into non-being eludes us and so death can only be represented as the visible and vigor-20 ous contrast between animation and corpse, and not even this, given the difficulties 21 already set out in filming at the point of death and after death. The very passivity of 22 the corpse does not invite empathy; it is merely a body that does not 'work', that is not 23 alive. The horror of the corpse is precisely this: it is always object, never subject, and 24 this is at the heart of Brakhage's (and, in a variation, Lucas's) proposition - that death 25 even when looked at cannot be seen in our vision. 26

Last words

31. The Human Tissue Authority was created to 'regulate the removal, storage, use and disposal of human bodies, organs and tissue' ('Human Tissue Act Code of Practice 5', published by the Human Tissue Authority, updated 2014).

32. Facebook recently (and some say belatedly) appointed a Head of Bereavement to develop a strategy for how the platform handles images made of people after they have died, with Facebook launching its memorialization feature. There are now numerous agencies such as Cirrus Legacy springing up for assisting in managing our digital legacies.

As a culture we continue to favour certain ways of making non-fiction moving images 32 of the interval of terminal illness, and of the instant of death. I have attempted to 33 argue that the inscriptions we elect for this challenging ethical space can be tested 34 and opened up, particularly if we more fully consider the terminally ill person, whose 35 status, needs and agency is changing. Where traditionally palliative care has taken 36 place in the hidden margins and secluded suburbs of society, the hospice movement is 37 now seeking greater visibility, in part prompted by the changing behaviour of patients. 38 People are mediating their deaths in new and frank ways, through social media, blogs 39 and death cafes, and so dying may once more become a social rather than an anti-40 social experience. Alan Kellehear's Compassionate Cities: public health and end of 41 life care (2005), (re)imagines a community in which death is a shared experience, a 42 co-experience, one that transcends the private unit of the family and the protective 43 veil of the medical setting. One of the clear shifts we are witnessing is at the level of 44 technology, which is increasingly in the hands of everyday users, who are media liter-45 ate, who take control of their self-representation and produce innovative documents.³² 46 In Totality and Infinity (1961), Levinas identifies an art of the production of being, 47 an accomplishment, our creative production. Levinas does not mean productivity in 48 terms of effectiveness in the capitalist work place, but rather in the sense of a mise-en-49 scène, an art of bodies in space. Such an art, tentatively trialled in different respects in 50 the films I have explored, asks that the dying person be permitted a creative becom-51 ing, and, if they are so inclined, an art of dying. These films are rare counters to the 52 trend of sentimentalizing, eulogizing or merely medicalizing the subject. They force 53

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us to think about how we can be witness to, and include the person dying. Formal 1 abstraction rarefies death, metaphor contributes further to its deferral, and abstrac-2 tion or symbolism also reflects our linguistic limitations in speaking of death, and 3 our total inability to report back from death as an experience. I began this conclusion 4 under the heading 'last words', and, advisedly, because last words are predominantly 5 the stuff of fiction. If we return to Sobchack's term, 'unspeakable transformation', then 6 spoken testimony seems less appropriate than the recourse to extra-linguistic, visual 7 8 expression. Death lacks sense. It is irreducible. The task then is to articulate this very inability to represent or articulate death, and in doing so make an opening onto the 9 visual field as an ethical domain, where an ethics of aesthetics might be proposed. 10 Such an ethics pivots on key elements: that the film artwork recognize the right of the 11 person who is dying to have any kind of image they wish (rather than the image be 12 13 decided upon by others, by society, on their behalf); that all formal registers are available in this space, not only the respectful distance of the observer or the management 14 of the viewer through established rhetorical devices; that the negotiation of this ethical 15 16 space, between film-maker and subject, be reflected in the film's frame; and, finally, that the returned look is not the only way of confirming the integrity of this space. This 17 18 final point makes the case for being with, and including raw or bare life, as well as the body after death, in the image. By transgressing social norms, film-makers working 19 with terminally ill subjects and palliative care professionals can help us learn about the 20 ways cultural limits surrounding death and dying are constructed and maintained, 21 and perhaps encounter dying and death differently. Subjects and film-makers working 22 in such a mode might creatively produce the everyday of end of life, with a license to 23 challenge the habits of death and dying, which, particularly within our culture, are 24 overdue such attention. 25

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29 Acknowledgement

31 This article is dedicated to Stuart Croft (1970-2015).

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