REPRESENTATIONS OF DYING IN CONTEMPORARY VISUAL CULTURE AND THE ETHICS OF SPECTATORSHIP

BY

JOHN EDWARD HORNE

A thesis submitted to the
University of Birmingham
for the degree of
MASTER OF PHILOSOPHY

Department of American and Canadian Studies
College of Arts and Law
The University of Birmingham
October 2012

ABSTRACT

This thesis is about the dying individual. The institutionalisation of death in the West has led to increasing public unfamiliarity with the actualities and banalities of dying. Accordingly, this thesis is concerned with the place where the dying individual is most commonly encountered: visual culture. How is the dying individual seen and screened? What structures are at play in their framing? And what is the spectator's ethical relationship with – and moreover, responsibility towards – the dying individual?

The introduction looks at imagery of dying which is used to "shock". I then examine how, over the past century, "dying has been pushed further and further out of the perceptual world of the living" (Benjamin, 1936/2007), before turning to the use of visual culture in national health projects which seek to return the dying individual to the communal fold. I identify problems, which in turn open up new possibilities for spectatorship as an act of active citizenship and solidarity. The last two chapters consider how to foster public solidarity with the dying individual in visual culture. Through photography, then film, I examine texts which unsettle the *status quo* and help lay the foundations for an ethics of spectatorship in the encounter with the dying individual.

ACKNOWLEDGMENTS

The before, during and after of this thesis owes overwhelming thanks to my supervisor Dr Michele Aaron. Thanks, Michele, for everything.

I am very grateful to Pauline Smith at NHS West Midlands who, with Michele, provided me with the foundations for this project through my involvement with the ‘Saying the Unsayable’ exhibition, discussed in Chapter Two.

Sections of this thesis have benefited greatly from conferences, conversations and critical interactions with people too numerous to mention. However, I would like to give particular thanks to Dr Maria-José Blanco and Dr Ricarda Vidal for their helpful comments and enthusiastic support of my work.

Thanks also to countless friends, old and new, who have encouraged me throughout the past three years.

Finally, thanks to Mum and Dad for always being there.

TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

I’m not afraid of death but I am afraid of dying. Pain can be alleviated by morphine but the pain of social ostracism cannot be taken away.

- Derek Jarman, quoted in Clint (1998, p7).

The difficulty about all this dying, is that you can’t tell a fellow anything about it, so where does the fun come in?

- Alice James, 1891, quoted in Yeazell (1981, p43)

INTRODUCTION:

THE SHOCK OF DYING

> The cradle rocks above an abyss, and common sense tells us that our existence is but a brief crack of light between two eternities of darkness. Although the two are identical twins, man, as a rule, views the prenatal abyss with more calm than the one he is heading for (at some forty-five hundred heartbeats an hour).
>
> – Vladimir Nabakov (1966, p19)

This thesis is about the dying individual. Specifically, of course, I refer to an individual for whom, through terminal illness or other means, death is rapidly approaching. However, from a certain philosophical perspective, we are all "dying individuals". As Elizabeth Kübler-Ross once observed, "dying is something we human beings do continuously, not just at the end of our physical lives on this earth" (1975, p146). Or for Bob Dylan, whoever is "not busy being born is busy dying" (1964). My own mortal course is taking me, day-by-day, towards death. Moreover, I am closer to my eventual end than I was last year, last month, last week. You are too.

In many respects this thesis is about the consequences of rejecting such an accepting perspective towards death, adopting instead a stance rooted in denial. It is about what occurs – as has happened in the West – when dying becomes "a deviation from the social norm" (Elias, 1985, p69). This thesis is thus concerned with the social consequences that follow on from when "dying individual" comes to connote a stranger to the community and an outsider to the public sphere. It is, that is, about how anxieties over "our" deaths have created structures of otherness which not only exclude the dying individual from the communal fold, but excuse that exclusion, so that “dying has become a form of social death” (Kellehear, 2007, p246). Whilst in recent years there may well have been a “revival of death” (Walter, 1994) in public discourse, barriers of taboo and an avoidance of actuality still work to keep the dying individual at a distance.

In what follows, I hope to trace some of the barriers currently keeping the dying individual separate from their fellow citizens. Borrowing Ariella Azoulay’s (2008) term, this thesis suggests that presently within the West the dying individual can be considered a “flawed citizen”, subject to isolation, stigmatisation and institutionalisation. It is through representation, not reality, that the dying individual is typically encountered in contemporary Western society. Jay Ruby rightly states that “our expectations about how death is supposed to look are aesthetically, not experientially, derived” (1995, p15). Indeed, as John Tercier (2005, p210) argues, for most, “the contemporary deathbed is, until we lie upon our own, a virtual one”. Accordingly, this thesis is focused on visual culture. How is the dying individual seen and screened? What structures are at play in their framing? And most importantly for me, what is the spectator’s ethical relationship with – and moreover, responsibility towards – the dying individual? These and other questions will be explored through examining encounters across a multitude of mediums, from national public health projects, to documentary photography and finally fictional entertainment.

Before setting out the wider historical and critical context, I want to briefly consider a selection of three images, in order to tease out some of the core issues at hand. The images are linked through intent, with each encouraging (or, in one case, discouraging) the spectator to become a consumer. The dying individual, so seldom seen, appears here not as a person but an object on a product. Or rather, the rarity of their appearance within the public sphere is capitalised on in a potentially problematic manner. The following three images thus offer distinct, but entwined, encounters between spectator and dying individual. None are easy to see. The first is an anti-smoking government heath-warning currently seen on Canadian cigarette packets. The second is a salacious tabloid magazine cover from June 2010, whilst the third is a 1991 advertisement for a clothing label. Each was circulated after the death of the respective dying individual. And each is, I suggest, *unsettling*. These unsettling encounters – and the social, ethical, moral and political questions they provoke – form the initial contours of the following enquiry.

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Fig. 1: Government health warning on Canadian cigarette packets.

In 2012, smokers in Canada became faced with the above government issued health warning on their cigarette packets [fig. 1]. The image is one of twelve, selected after it was felt that existing warnings were not confrontational, or graphic, enough. Barb Tarbox appears in two of the pictures (in the second, equally emaciated, she is captured sat with cigarette in hand and mouth agape). Other images include a close-up of oral cancer and a man fated to forever breathe through a hole in his throat as a consequence of his smoking.

In the image, Barb's withered and drained face appears desolate and abandoned; her hands positioned awkwardly on an equally thinned torso. Indeed, her open eyes offer the only clear indication that Barb is dying and not already dead. Yet the spectator is not asked to offer pity, or compassion, or solidarity, or love to Barb. Rather, the warning's words reframe the spectator's gaze on her dying body into one approaching moral condemnation. "This is what dying of lung cancer looks like," the red text reads, adding below: "You can quit. We can help."

The health warning traffics in the expectant shock of the spectator to impart its message: Barb deserved this, it seems to be arguing, but "you" can escape her fate. Barb's death, it suggests, need not have been in vain. Rather, the unpalatable sight of her dying is offered – almost sacrificially so – as a "warning" in order that future deaths may be prevented. The picture was considered for a similar campaign in America by the FDA, submitted with the identifier "deathly ill woman". It was, however, ultimately rejected, with one respondent saying it "offend[s] against human dignity," and another that it was "too sensational to be effective" (quoted in Healy, 2011). Even the men who took the photograph – who had been documenting Barb's dying for many days – found it shocking and hard to stomach. Interviewed in 2011, Greg Southam and David Staples recounted their reactions when they first saw the image on a computer screen:

> "I said to Dave, 'You've got to turn that off. I can't stand to look at it'," Southam recalled. Staples remembers thinking, "We should destroy that. We could never run that. This is wrong." (quoted in Healy, 2011)

But *is* the image of Barb shocking? Or, put another way, how is it that a picture capturing a fundamentally not uncommon occurrence – approximately 200 Canadians die every day from cancer[1] – can function as a shocking "warning" within the public sphere? This is clearly a core question to be considered throughout what follows. But, put simply, I suggest that public unfamiliarity with the actualities of dying, coupled with the photograph presenting Barb in isolation, combines to unsettle the spectator's sense of individual security. Furthermore, the warning is addressed to – or rather, it assumes – a spectator who is "living", which is understood to mean – unlike Barb – "not-dying". Thus part of the intended shock stems from the fact that the warning challenges the spectator to place themselves in Barb's place, suggesting that they – the "living" – might one day find themselves "dying", with all that that entails.

However, this isn't the first encounter Canadian citizens have had with Barb's dying. Before her death in 2003, Barb became a passionate anti-smoking campaigner, focusing much of her energy speaking to children and teenagers. Her final weeks and months were spent in the presence of Southam and Staples for a series of articles, subsequently turned into a book. The title of the book perfectly encapsulates the notion that Barb's dying was not done in vain, but rather as a public spectacle to save others from such a fate: *Barb's Miracle: How Barb Tarbox Transformed Her Deadly Cancer into a Life–Saving Crusade*.[2]

A short documentary of her speaking tour was also shot and used as an educational tool in schools and elsewhere.[3] In it, she can be seen to be consciously

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[1] Figure taken from Canadian Cancer Society general statistics website: http://www.cancer.ca/Canada–wide/About%20cancer/Cancer%20statistics/Stats%20at%20a%20glance/General%20cancer%20stats.aspx?sc_lang=en [Accessed September 28th, 2012]

[2] Staples and Southam (2004)

[3] *Barb Tarbox: A Life Cut Short By Tobacco* (2003).

using the sight of her body as an object to shock, as she draws on a dramatic rhetoric of punishment to warn audiences that if they smoke they will end up haggard and dying like her. At one point, her bald head exposed, Barb tells a story of going shopping and having a small child point at her, saying that Halloween is over. The audience filled with young children gaze at her with sympathetic eyes. Pointing to her head she says, “Hey, its okay – this is what I get now.” She pauses and leans in to her audience for effect. “I smoked.”

Whilst the cigarette packet image contains none of this background information, its rhetorical stance is the same. Significantly, therefore, despite appearances, it accords with Barb’s actions and intentions whilst alive and was part of a consensual project to continue her message after death. Indeed, her family considers the health warnings as a continuation of her own legacy and they took an active part in the campaign publicity when the new warnings were announced. Speaking at a school in September 2011 alongside Canadian Health Minister Leona Aglukkaq, Barb’s husband told the assembled schoolchildren that the image of his wife was being used because, “it freaks out a lot people”. He continued:

> We’re hoping her image will have an impact on a lot of youth and that’s really what Barb wanted to do. [...] It's a stark reality of what cancer looks like. If you think smoking is cool, 20 years down the road, you don't look so cool when you're lying in a hospital bed deteriorating. (Quoted in Schmidt, 2011)

An entirely different family dynamic and photographic context can be found in the following encounter:

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Fig. 2: Actor Gary Coleman on his deathbed. *The Globe*, June 2010

Fig. 3: *The Globe* cover reprinted in *The Mail Online* (2010)

Gary Coleman, the actor famous for his role in the television series *Diff'rent Strokes*, died on May 28th, 2010. Within a fortnight, a photograph of the actor's dying was published on the front cover of *The Globe*, a glossy American tabloid magazine [fig. 2]. Coleman is captured in his hospital bed, intubated and apparently unconscious. Next to him, and gazing into the camera lens, is his ex-wife Shannon Price. As if the image wasn't sensationalistic enough, *The Globe* insists on adding additional sensational framing; "It was murder!" screams an all-caps headline, whilst underneath is the heading, "Wife Shannon sobs: I didn't push him." Coleman, who had a long history of health problems, was admitted to hospital on May 26th, after falling down stairs and suffering a serious head injury. Shortly afterwards, Shannon made the decision to remove him from life support. Following Coleman's death, Shannon's actions generated much gossip and media speculation over her motivation and alleged fiscal interests. These suspicions were exacerbated when it was claimed that she was offering to sell deathbed images to the highest bidder, reportedly selling the photograph (and others) for $10,000. Coleman's family and friends were especially (and publicly) appalled. When *The Globe* issue was published it generated a raft of articles and commentary, all proffering their moral outrage, whilst nonetheless routinely reproducing the front cover.[4]

Through such reaction, others publicly got to define the narrative of Gary Coleman's passing, whilst insisting it was a private affair. Accordingly, he lost his individual agency, slipping from a subject to be engaged with on an interpersonal basis, to an object on which to hook a sensationalistic story for commercial gain. (Perhaps for Coleman in death, as it was for him in life). In the front-cover photograph, Coleman, his head bandaged and his face half-concealed by tubing, is further enclosed by shadow, stripping his subjective presence even more. Whilst Coleman is the ostensible focus, the image actually beckons the spectator's eye towards Shannon, and a questioning of her complicity and guilt in profiting from his dying. However, the precise context in which the photograph was taken, and the nature of its sale, is currently unknown and potentially unknowable. Who took it (and others)? Who else was in the room? Did the person who sold it perhaps purposely select the image where Shannon looks the most emotionally blank and thus suspicious?

It is almost impossible to untether the image from the context of its public – and commercial – circulation. This is apparently not, that is, a private photograph taken by a "loved one" as a memento of the soon to be "dearly departed", which was leaked, or stolen, and thus snatched from its intended viewing context for the purpose of public display. The picture does not offer the spectator any assurances that it was taken with the consent of all involved; instead it suggests quite precisely

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[4] Whilst far from a precise metric, an indication of the coverage can be gauged from the fact that a Google search for '"Gary Coleman" + "The Globe" + "Shannon Price" + photograph' produces over 17,700 results. Search on http://www.gooogle.com done on September 24th, 2012.

the opposite. Furthermore, whilst not entirely uncommon, there is no publicly acknowledged tradition today in the West for taking such pictures, and particularly not in publishing them. That is, any image of a person "posing" with a dying individual can – no matter how close and familial – automatically appear out of place and perhaps more than a little macabre and inappropriate to outside observers.

The public unfamiliarity of such photographs results in the image of Coleman and his ex-wife echoing the picture from Abu Ghraib prison where Sabrina Harman posed, smiling, over the dead body of Manadel al-Jamadi.[5] The key similarity is that in both, a (white) woman greets the spectator's (and camera's) gaze, whilst a dead or dying (non-white) individual is unable to: both convey a vibe of violation, whilst providing – indeed, framing – someone whom the spectator can apportion blame upon. Both, that is, redirect the spectator's own unease at being witness to the dead and dying: the photograph becomes about the conditions of its taking, not its ostensible subject. This latter point is reinforced through the manner in which *The Mail Online* covered the story by reproducing *The Globe* front page whilst blurring out Coleman's face "blurred […] so as not to offend" [fig. 3]. Are they worried, one wonders, about offending Coleman's family (and if so, why run the story at all)? Or is, perhaps, the sight of a dying individual – or the taking of a photograph of one – "offensive" in and of itself? There is, however, a third possibility as to why *The Mail Online* blurred Gary Coleman's face. It was an unusual decision as most other media outlets reproduced the front cover untouched. This possibility is captured in a comment by a reader made on the CBS news story

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[5] As Errol Morris (2008) has examined, the photograph of Sabrina Harman and Manadel al-Jamadi conveys Harman's guilt, yet had she not taken this image – and the others where she forensically examines al-Jamadi's injuries – his death (and cover-up) at the hands of CIA interrogator Mark Swanner would have remained unknown.

about the photograph: “Everyone got to this site by a click, we all are guilty of gawking.”[6]

The fact that the dying individual is kept out of public sight has lent a transgressive air to their appearance. The spectator therefore enjoys a voyeuristic aspect in viewing the socially taboo – a spectatorial pleasure which is nonetheless disavowed. The framing of the photograph and the wider framing of *The Globe* front-page goes a long way to sustaining this disavowal. However *The Mail Online* went further and digitally effaced Gary Coleman, so their readers wouldn’t feel too “guilty of gawking”.

The final image to be considered is an advertisement from 1991 for the clothing company Benetton which provoked great controversy when it was released on billboards and in newspapers and magazines across the world. Indeed, LIFE magazine, which first published the photograph on which the advertisement is based, claims that “by some estimates, as many as one billion people have seen” the image (Cosgrove, n.d.). Unlike the previous two photographs, this picture has received considerable academic discussion, especially in relation to strategies of “shock advertising” employed by corporations, and the history of HIV/AIDS representation[7]. My interest here is more closely confined to the conditions by which the painful actualities of a young man’s dying – “my son more or less starved to death at the end,” his mother has said – was transformed into a commercial spectacle to “shock” consumers (*ibid.*).

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[6] Internet comment by “Montilla43” to CBS News, June 8th, 2010. [Online] http://www.cbsnews.com/8301–31749_162–20007255–10391698.html [Accessed September 28th, 2012]

[7] See for example Cooter and Stein (2007), Gibbons (2005, pp75–97), Campbell (2008, pp33–34), Giroux (1994), Isé (1993), Sandıkcı (2011), Tinic (1997)

IMAGE NOT FOR REPRODUCTION

Fig. 4: David Kirby’s Final Moments. Therese Frare, 1990.

In November 1990, LIFE magazine published the above photograph, taken by Therese Frare, of David Kirby, 32, surrounded by family on his deathbed [fig. 4]. David, a gay activist, was being cared for at Pater Noster House, a hospice for AIDS patients in Columbus, USA. The family are captured saying their final goodbyes. David passed away an hour later. The following year, the photograph won the World Press Photo Award and in 2003 LIFE included it in their book *100 Photographs That Changed The World* (Sullivan, 2003). The composition of the shot – with David’s father cradling his son’s head visually echoing the support David’s sister provides his niece – is enhanced by the black and white contrast between the two groups. Indeed, whilst belonging to a hospice worker called Peta, the black sleeve at the left of the frame hints at Death himself approaching.

The image is as much about family solidarity and the suffering of those who live on, as it is about David’s dying. Or rather, the spectator is positioned with the family, looking on, in contrast, say, to the more unsettling encounters with Barb Tarbox and Gary Coleman discussed above. The image is by no means the only one taken of David in the hospice – or indeed of this moment – but it became *the* image of his dying and in terms of global exposure, came to be one of *the* images of

(Western) death from AIDS. Accordingly, it can be said to have presented a "domesticated" representation of HIV/AIDS – the sufferer a stilled, emaciated, victim, awarded security through the (heterosexual) fleshy family unit. For now, however, this is not my interest. My focus is instead concerned with what happened to the photograph next – its use in a campaign by Benetton to sell clothes – and the corporate discourse backing that strategy. As such, I will quote quite extensively from people connected to the campaign. Their rhetoric is rather revealing of how much, in 1992, the mere sight of a dying individual could be expected to "shock" citizens with "reality". David Kirby's subjective presence is lost, his dying body turned into a weapon advertisers choose to use to "punch people in the face", on the pretence of creating "an awareness of issues" rather than their own fiscal interests.

One of the readers of the November 1990 issue of LIFE was graphic designer Tibor Kalman, then editor-in-chief of *Colours*, a magazine funded by Italian clothing company Benetton. Working with Benetton's creative director Oliviero Toscani, Tibor had been developing a unique and provocative advertising campaign for the company under the name "United Colors of Benetton". The campaign was becoming increasingly untethered from the product it was marketing. Images would be created for their social message, with only a small box identifying the picture as "United Colors of Benetton", without any indication as to what that actually is. A series of studio produced photographs, for example, captured individuals of different races together, with the intent of fostering a message of multiculturalism (and as such, branding Benetton as racially tolerant and morally conscious).[8] Then, in 1991, the campaign began using much more politically motivated images, such as nun and a priest kissing. This triggered increasing controversy – and publicity – for

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[8] These images were not unproblematic, with many commentators viewing them as conveying racist and colonial messages. See Lester (2006, pp69-72).

Benetton. Moreover, it generated profits. In 1990-1991, Benetton's profits increased by 24% to \$132 million (Giroux, 1994, p11). A decision was then made to move away from staged images and to select existing photojournalism. The campaign was titled "The Shock of Reality". Speaking in 1992, founder and managing director Luciano Benetton explained:

> This year we have chosen to use real photographs from real life to avoid being accused of speculation and of staging reality. (quoted in Back and Vibeke, 1993, p75)[9]

IMAGE REMOVED FROM PUBLIC COPY

Fig. 5: David Kirby – A 'Pietà', Benetton advertisement, 1992.

Kalman recalled the image he had seen in LIFE magazine of David Kirby dying of AIDS and approached the family and photographer for permission to use it for the 'United Colors of Benetton' campaign [fig. 5]. Writing in 2001, Kalman's wife Maria described the atmosphere in the creative team at the time around the selection:

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[9] Cited in Camnitzer (2007, p305).

> There was a collaborative feeling among all involved that you had to really *punch people in the face* with this incredibly epic and devastating moment and make them aware of it. You would stop and look at it. You would have a conversation about it, whether you hated it or loved it. It would promote heated dialogue. (Kalman, 2001; emphasis mine)

A creative decision was taken to "colourise" the black-and-white photograph. Maria explains this was, "to take it out of the journalistic field and make it appear more as an ad, so that it was even more shocking in its context and would hopefully be more arresting" (i*bid.*). The colorization can perhaps be seen as the price the photograph – and moreover, David Kirby – paid for its widespread circulation within the public sphere. The image, that is, shifts even further in its register from capturing actuality to artificial representation. The aesthetic limitations of the colourisation process lend the image a muddy sheen, producing – perhaps intentionally – a picture operating in something of a kitsch register. The shift from black and white to not-quite-right colour also plays into the historic binaries associated with the two pictorial formats. That is, black and white has signified serious realism and documentary intent, in contrast to colour connoting escapist fantasy and commercial spectacle.[10] Roland Barthes' remarks on the two formats strike a pertinent chord: "I always feel [...] color is a coating applied *later on* to the original truth of the black-and-white photograph. For me, color is an artifice, a cosmetic (like the kind used to paint corpses)" (1981/2000, p81, emphasis in original). Writing on the use of black and white photography in the nineties, Paul Grainge argues that "it has become associated with the very categories that have

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[10] Siegfried Kracauer's observations in 1960 on film are pertinent here: "contrary to what should be expected, natural colors, as recorded by the camera, tend to weaken rather than increase the realistic effect which black-and-white movies are able to produce" (1997, *xlvii*).

been unsettled by the global media sphere: authenticity and time" (2005, p251). It could be said, then, that colourising the photograph helped restore the image to a formal aesthetic of immediacy and inauthenticity, enabling permissible circulation within the "global media sphere": the only unsettling element was the dying individual himself. Whilst the Benetton advert cannot be charged with "staging reality" *per se*, it certainly seeks to take actuality and coat it with the sheen of spectacle[11], establishing a secondary layer of representation between the spectator and the dying individual.

Benetton sought to ensure that the image also took on a symbolic tenor, to amplify the possibility of public outrage. For example, company spokesperson Peter Fressola said, "We're trying to show the literal and figurative branding of AIDS victims in our society and the damage it can do. We want to provoke discussion on the subject".[12] Indeed, the advertisement was titled "David Kirby – A 'Pietà'", a reference to representations in Christian art of the dead body of Jesus Christ being cradled by his mother Mary. The pale colouration of David's face, coupled with the brown of his hair, amplifies such allusions. In fact, it is alleged that David's face was actually altered by the designers, which for Joan Gibbons adds "enormously to the rupture that this image caused in the spectacle of consumerism" (2005, p88). The painting visible in the background furthers a religious interpretation. Entitled "Come Unto Me", it is a 1967 work by Christian artist Joann Reed portraying the outstretched, welcoming, hands of Jesus. In the photograph, David's head is coincidentally tilted to the exact angle of the hands, suggesting the potential for a spiritual continuation into an afterlife.

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[11] I am using "spectacle" as a conscious allusion to Guy Debord's notion of the "society of the Spectacle", a point which will be developed below.

[12] Quoted in Rutherford (2000, p320).

Oliviero Toscani, the creative director of the campaign, added an extra layer of controversy in relation to Benetton's intentional Christian symbolism:

> Personally I call this picture "La Pietà" because it is a Pietà which is real. The Michelangelo's Pietà during the Renaissance might be fake, Jesus Christ may never have existed. But we know this death happened. This is the real thing, and the more real the thing is, the less people want to see it. It's always intrigued me why fake has been accepted and reality has been rejected. At Benetton, we are trying to create an awareness of issues. AIDS is one of today's major modern problems in the world, so I think we have to show something about it.[13]

Toscani's words seem designed to stoke Benetton's stated aim for the advertisement to "provoke discussion", especially amongst religious groups and individuals, and campaigners for HIV/AIDS awareness. Moreover, his comments are structured to put such groups on the back foot, forced to respond to Benetton's claimed benevolence and social responsibility in seeking to make visible otherwise unseen suffering. The reaction the advertisement received, particularly in Europe and America, was fierce. In the UK, leading AIDS charity The Terence Higgins Trust called for it to be banned, *The Sunday Times* called for Benetton to be boycotted and *The Guardian* was forced to write an editorial defending its decision to run the advertisement after receiving many letters of complaint. *Vogue, Elle*[14] and *Marie Claire* magazines all refused to run it, whilst in Germany the company was taken to

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[13] The original source for this quote is Sischy (1992, p69). Incomplete quotes are cited in Rutherford (2000, p161) and Giroux (1994, p20). It also formed part of the media pack circulated when an exhibition of Toscani's work was held at the Carrier Gallery in 1994 (Rutherford, 2000, p320).

[14] *Elle* magazine even went to print with two blank pages where the advert was due to be, at a loss of $150,000 in revenue (Bonner, 1992, p67).

court (Cosgrove, n.d.; Cooter and Stein, 2007, p195). Indeed, a German court banned this and several other Benetton adverts from public display, ruling that they "were morally offensive and violated the principles of fair competition by using compassion for commercial purposes" (BrandRepublic, 2000). In America, AIDS activist group ACT-UP sought to subvert such "commercial purposes" by defacing billboards bearing the advert, writing "There's only one pullover this photograph should be used to sell," followed by a picture of a condom (Cooter and Stein, 2007, p192).

In the escalating face of criticism, Benetton's repeated refrain was that David Kirby's family had consented to the image being used because it supported his wish to raise awareness of HIV/AIDS. Indeed, the family even travelled to New York to take part in a press conference at the start of the campaign. David's father William was quoted as saying: "The point of the ad isn't to sell clothing – Benetton took quite a risk with it." (quoted in Bonner, 1992, p67). Therese Frare, the original photographer, would later say she was "falling apart" during the height of the controversy, but took reassurance from something William said to her: "Benetton didn't use us, or exploit us. We used them. Because of them, your photo was seen all over the world, and that's exactly what David wanted" (Cosgrove, n.d.).

The image by itself doesn't necessarily connote AIDS: it simply pictures a young man dying. The specifics of David's dying – or rather, the specific illness which killed him – come from outside the representational frame. When the original photograph appeared in LIFE, such context was already there on the page. However, the Benetton advertisement appeared on billboards across the world with only the corporate logo offering any indication of how the image should be interpreted. This is to say, therefore, that Benetton was dependent upon the advertisement becoming subject to public discussion, commentary and critique in order for it to actually signify the plight of individuals dying from AIDS. Or, put another way, in order to be “correctly” read, the image required extra-textual knowledge on the part of the spectator. Furthermore, in order for the picture to “provoke” and “shock” any spectator, the content within the frame needed to be seen as something which would puncture everyday life and trouble the public sphere. The presence of the dying individual, it appears, was enough.

Lost amidst the controversy was David Kirby. His face was present through layers of representation and symbolism – and perhaps also disguised behind aesthetic manipulation – but the actuality of his existence was ostensibly hidden. Instead, David has become an icon signifying something which shouldn’t be, referencing realities which typically remain hidden. Yes, HIV/AIDS, but also the basic, human, banality of dying. The advertisement was constructed enough to keep the universality of the latter at bay – no one need feel “guilty of gawking”. Moreover, the address of the campaign sought to treat David – the dying individual – as different from the “living” spectator: dying is something that happened to *him* – not you, not us – but *we* have a responsibility to show compassion to such citizens, rather than shun *them* so they are forced to exist in a condition of invisibility. As a consequence, David’s subjectivity is stripped and reduced to object status, as he comes to signify “dying from AIDS” or simply “dying”, rather than himself. His mother Kay would later capture this in personal terms: “What I objected to was everybody who put their two cents in about how outrageous they thought it was, when nobody knew anything about us, or about David” (Cosgrove, n.d.).

We learn little about Barb, Gary and David, or indeed about dying, in these encounters: their appearance within the public sphere was to serve other purposes. The fact that their presence can be predicted to “shock” – to the extent that a citizen could say that the photograph of Barb dying “offend[s] against human dignity” – speaks to the public unfamiliarity with dying in the West. The pictures were able to provoke by little more than this. None of them capture anything especially remarkable – thousands of individuals are experiencing and encountering dying daily – however the present public sphere prefers to absent such actuality from everyday life. When the dying individual does appear in representation, they enter not as equals but as *flawed citizens* – precisely the same status they are socially accorded through institutionalisation and isolation.[15]

Given all this, for the spectator the act of looking at an individual who is dying is fraught with complexities. It unsettles socio-cultural taboos around death and, as such, is likely to cause anxiety or unease. Such an encounter is also a potential reminder of the spectator’s own mortality and corporeal finitude, challenging the self’s wish for immortality (see, for example, Lifton, 1980; Bauman, 1992). This spectatorial quandary is typically negotiated through a broad exclusion of the dying individual from visual representation in the West, echoing their condition of invisibility within the social sphere. However, when the dying individual is figured in visual culture, various textual strategies tend to be deployed, framing the encounter through an objectifying lens. This enables the spectator to mitigate or disavow the subjective presence and agency of the dying individual, and, moreover, keep questions of their everyday responsibility towards them at bay.

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[15] The images of Barb, Gary and David are also bounded by additional socio-cultural discourses of gender, race, sexuality and physical impairment which further shape the ideological contours of the encounter.

The three images – of Barb Tarbox, Gary Coleman and David Kirby – frame different, but connected, encounters between spectator and dying individual. In each, the dying individual was made visible within the public sphere through a commercial context. Designed to foster "shock" by puncturing "the spectacle of consumerism", the dying individual is seen as a means of encouraging the spectator to become a consumer (or not) of a particular product: cigarettes, *The Globe* magazine and Benetton clothes. Moreover, the "shock" of a dying individual is intended to provoke public discourse on a topic – smoking, AIDS and Coleman's ex-wife Shannon Price – deflecting the subjective presence of their appearance. These are all carefully constructed encounters to ensure the spectator doesn't feel "guilty for gawking". Moreover, whilst they intentionally "shock" and unsettle the public sphere, they offer the spectator certain assurances for their own mortality. Accordingly, the images enforce a distinction and division between "living" and "dying", addressing a community of citizens who are "not-dying" (that is, "living").

The dying individual, who in actuality endures a condition of invisibility, enters the realm of representation always already constricted through objectifying discourse. Moreover, their own personal agency, individuality, sensibility and subjective presence gets lost, provided only through the extra-textual discourse which is made available by others. The spectator's encounter with the dying individual is thus constructed, displayed and narrated by others for others. But what if the dying individual was part and parcel of the communal fold? That is, what if barriers of taboo had crumbled and dying became just another banal facet of everyday life? What would the visual terrain look like then?

The tension inherent to these questions drives this thesis. In what follows, I will locate them more fully in their contemporary socio-cultural context, tracing the recent history of how dying has been dealt with in the West. We will see how the dying individual has "been pushed further and further out of the perceptual world of the living" (Benjamin, 1936/2007, pp93) since the beginning of the twentieth century. Moreover, we will observe the damage done by this communal denial of the universality of death based on the belief that it can be contained and mastered: of how individualism – and the self's projection of immortality – has curtailed Western citizens' ability to form authentic, supportive and pluralistic communities. Whilst tracking the physical disappearance of the dying individual from "the perceptual world of the living", we will trace their appearance in visual culture, where their encounter is always already framed by the Spectacle – "a social relation between people that is mediated by images" (Debord 1967/2000, p7). Contrary to appearances, the Spectacle is "a visible *negation* of life" (p9). This works to serve the ideological purposes of capitalist society through distancing real, lived experiences, engendering banality and passivity and encouraging individualism over community. Representations of the dying individual, I argue, typically work to reassure the spectator that death *can* be contained within a framework. Which is to say that the "perceptual world of the living" offers citizens and spectators alike certain securities by constructing the dying individual as different: as other from the "living".

My focus will increasingly come to be centered upon how the *status quo* can be unsettled through visual means. My interest lies specifically in questioning and formulating the *responsibility* of the spectator towards the dying individual. Moreover, this spectator will be located as an agent within the public sphere, positioned on a pivot between submission to the Spectacle and civic engagement. Whilst my diagnosis of the *status quo* will be, bluntly, negative, I aim to chart an optimistic path by rehabilitating the political possibilities of the spectator. Drawing on current scholarship on the ethics of spectatorship, I will consider how spectatorial responsibility can be awakened, with the ultimate aim of a radical refiguration of the structures of otherness that presently frame and contain the dying individual within the perceptual world of the living. An argument made by Chris Townsend is particularly pertinent here:

> Perhaps the face of the slowly dying man is a face we would rather not see, but a face that, precisely because it makes us uncomfortable, because it tells us where responsibility lies, that we must see. (*sic.*, Townsend, 2008, p75)

Chapter one will provide the historical and critical context for the following study, pulling together relevant cross-disciplinary literature on death and dying to map the socio-cultural *status quo* in the West. It will also be an opportunity to more clearly define key terms – such as “dying individual” – before moving forward. Chapter two turns to contemporary attempts to restructure and reform end of life care, so that the dying individual is no longer condemned to institutionalisation, isolation and stigmatization. Focusing on the British National Health Service, it will consider specifically a project run in the West Midlands which sought to use photography as a means of challenging community taboos around death. Some problematic aspects of the project will raise key questions around how visual culture functions and how, despite intentions, imagery can unconsciously perpetuate the *status quo*. However, these problems will open up new possibilities, revitalising community through a rethinking of citizenship. Chapter three picks up the challenge of fostering solidarity with the dying individual in visual culture. It considers three photographic projects – *Gramp*, *Grace Before Dying* and *The Dad Project* – which aimed to change public attitudes. The images will be critically read for the differing ways each photographer wrestles with the problem of being both camera and companion, whilst attempting to frame the dying individual so as to sustain their subjective presence.

Moving on from still photography, chapter four turns to the moving image, looking particularly at fictional cinema. The dying individual will be seen as being generally screened for the benefit of the spectator as a salve against death anxiety. After paying particular attention to *Death Watch* (1980), *All That Jazz* (1979) and *My Life* (1993), the chapter then considers two texts which unsettle the typical dynamic, *Wit* (2001), and *Lightning Over Water* (1979), and help lay the foundations for an ethics of spectatorship in the encounter with the dying individual. Central to everything is the following question: Is it possible to unsettle the structures of otherness governing the perceptual world of the living, or must the encounter with the dying individual be always already foreclosed?

CHAPTER ONE

ENCOUNTERING THE DYING INDIVIDUAL WITHIN THE "PERCEPTUAL WORLD OF THE LIVING"

Walter Benjamin, writing over seventy years ago, captured a state of affairs that persists in the West to the present:

> In the course of modern times dying has been pushed further and further out of the perceptual world of the living. There used to be no house, hardly a room, in which someone had not once died. [...] Today people live in rooms that have never been touched by death, dry dwellers of eternity, and when their end approaches they are stowed away in sanatoria or hospitals by their heirs. (1936/2007, pp93-94)

Over the course of the last century, dying became a problem that was treated increasingly through institutional means: it moved out of the house and into the hospital, hospice or care home.[16] Gradually this passage "out of the perceptual world of the living" came to be perceived as normal. Society shifted structurally in ways which complicated, if not flatly discouraged, the ability to die in one's home, or the place of one's choosing, or in a manner that reflected one's wishes. Furthermore, increasing taboos around discussing death established barriers that continue to cocoon dying situations away from the community, bracketing off

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[16] For a range of historical and sociological accounts., Ariès (1981), Kellehear (2005, 2007, 2009), Elias (1985), Illich (1977), Kearl (1989), Bauman (1992), Walter (1994), Kastenbaum (1995), Seale (1998); Harmon (1998), Bradbury (1999).

individual grief and suffering until an acceptable public face of bereavement is reached. Alongside this, cultural engagement with the topic typically absented away the actuality of natural death (and the idea of death as natural), tending instead towards the entertaining, or shocking, spectacle and the sentimentalised and sanititised struggle against illness.[17] Put another way: the lived experience of the dying individual became framed both socially and culturally in a manner that maximised anyone's capacity, citizen or spectator, to disregard it.

In this chapter, I will set out a more precise map for the analysis that follows. What do I mean by "dying individual"? What different treatment have they received across the past century? What are the political and psychological underpinnings of Western taboos around death? Why is violent dying seen far more frequently than natural deaths? Is the West really guilty of a socio-cultural denial of death? Amidst this, I will also locate this study within existing scholarship, and outline and define the key terms and notions which will form the core of my theoretical approach. As such, this chapter will conclude having imparted a solid sense of the "spectator" and "citizen" who encounter the "dying individual" within the "perceptual world of the living".

This thesis is intended to act as something of a corrective to the absence of literature on dying in visual culture. However, it does not attempt to fill the necessary historical gaps and is limited to photography and film. This thesis will also sadly not explore many essential and necessary questions around gender, race, class, sexuality, religion, age and disability.[18] As I am arguing for the dying individual as a universal figure, this thesis will also not be differentiating between

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[17] See, for example, see Gorer (1965/1995), Sobchack (2004, pp226-257), Tercier (2005), McLlwain (2005), McInerney (2009), Aaron (forthcoming).

[18] Reflecting dominant ideology, it could be said, however, that the "perceptual world of the living" values above all – that is, constructs as the most "grievable life" (Butler, 2004) – a wealthy, straight white able-bodied Christian male.

different causes of death, nor explore their cultural meanings regarding what Susan Sontag (1978/2002) termed “illness as metaphor”.[19] Rather, my intent is to define and describe the parameters of the encounter between spectator and dying individual, locating it within a contemporary socio-cultural context in order to pose certain ethico-political questions.

It should be noted at the outset that precisely what is meant by “dying” is problematic. I have a fundamental wish to destabalise the term “dying”: to shift it from being something projected onto an individual and instead accepted as something inherent and integral to all. Indeed, over the course of this thesis, echoing my remarks at the start, “dying individual” will come to be understood as applicable to every single human being.[20] To describe somebody as “dying” is to identify complex physical, psychological, social and existential needs, yet that same labeling presently serves to stigmatise, resulting in isolation and abandonment (Kellehear, 2007; Sinclair, 2007). As such, “dying individual”, as a descriptive term, instantly labels, categorises and objectifies. Similarly, it assumes a universality of experience without accounting for individual particularities. It is being used here to refer to a terminal situation where mortality is approaching, but this should be understood in the broadest possible terms, inclusive of all social and psychological meanings.

Writing a few weeks after he received a diagnosis of just three months to live, Philip Gould in some respects captured the existential temporal bracket from the perspective *of* the dying individual: “When you reach that place where you have been told – and you believe – that you are going to die within a certain amount of time: that is the Death Zone” (Gould, 2012, p119). By Gould’s coinage, the “Death Zone” potentially encompasses the entirety of one’s life. It is, crucially, not just

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[19] See also Sontag (1989) and Stacey (1997).

[20] I will later introduce the work of Emmanuel Levinas, through whom we will come to see the “dying individual” as the Other in the context of the Levinasian face-to-face encounter.

knowledge that one will die but that “you believe” your time is limited – whether that be ‘three-score years and ten’, or just three months. In modernity, however, the West has, as we shall see, sought to deny the natural fact of dying, preferring fantasies of immortality instead (Becker,1973; Lifton, 1980; Bauman, 1992). As Stanislav Grof and Joan Halifax suggest, “aging, fatal disease, and dying are not seen as part of the life process but as the ultimate defeat and a painful reminder of the limits of our ability to master nature” (1978, p6). The impact this has on the everyday life of the dying individual is legion. It is important to remember too that dying – in the case of a heart attack or stroke, or violent accident – can come suddenly and swiftly to an individual.

Gould also hits upon a crucial point: the knowledge that he was dying – that his cancer was unavoidably terminal – came from another person. What if Gould, for lack of access to health care, or fear of medical professionals, only received a diagnosis a month before his death: would he still have been “dying” the previous two months? And what if pioneering experimental surgery was able to remove the incurable tumor and restore his damaged organs: could he say that he was “dying” during the preceding period, or does dying require the finality of death to be meaningful? Geoffrey Scarre (2009) wrestles with these and other questions, which follow as a consequence of the lack of definitional fixity of the word. For Scarre, “our use of the word ‘dying’ is guided not by a crisp set of necessary and sufficient conditions but by a range of paradigms, models and striking examples”, reflecting “the status of dying as a social and existential condition as well as a medical one, with multiple significances” (p148). The definitional difficulties extend to health-care settings, where a plethora of varying terms – such as “life-limited”, “terminally ill”, “end of life” and even “eventually fatal condition” – are used to try and capture the “death zone” without using taboo words. The phrase “active dying” is also routinely used to differentiate the very final phase of the body’s shutdown. Indeed, even the rather awkward “living-dying person” has been suggested (Wilson, 2009).

The same difficulties apply – increasingly – to “death”. Over the twentieth century there has been an increasing tendency to cede definitions of death and dying to medical authorities. Advances in medical technologies have meant that a patient can be kept “alive” almost indefinitely through artificial means, with “life-support” machines sustaining basic biological functions, such as breathing. Contemporary definitional dilemmas revolve especially around the question of “brain death”, concerning both how it can be determined and whether cerebral functions are a requisite for “life”.[21]

“Brain death” describes a comatose and vegetative state where, without mechanical life support, a person would die. It raises particularly prickly issues in the West where mental sentience is a critical marker of individual agency. Allan Kellehear, a leading scholar of dying, sees this cerebral bias reflected in the literature, noting that “cognition, will and consciousness” have been typically emphasied “over the social basis of attachment, meaning-making and identity” (2008, p1541). Kellehear observes that “the determination of death has historically been based on a community criteria of death”. He continues, adopting the voice of the community to dramatically emphasise the powerlessness of the dying individual in determining the criterion of their own death: “You are dead when WE say so, and

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[21] Such questions of bioethics have been the subject of much debate. See, for example, Noys (2005, pp53-99).

not simply when SOME of us say so, or even when your doctor says so" (2008, pp1540-1, capitals in original).[22]

Again, then, we see how the dying individual is defined and construed through the lens of the "living". This can be, of course, a necessity of circumstance. However, as I will be arguing, with the dying individual having "been pushed further and further out of the perceptual world of the living", their public unfamiliarity and civic disappearance works to sever their subjective presence from those whom they encounter: the "uncomfortable" fact of their dying is publicly contained and made safe by ensuring that the encounter is always already foreclosed. Moreover, because dying is near invisible within the public sphere, medical and professional institutions gain increasing authority in shaping social perceptions.[23] As Kellehear has argued:

> Dying, as a shared social, that is, interpersonal affair is becoming endangered as a publicly recognised form of conduct. […] Dying is now increasingly state-defined, with definitions so institutionally narrow in their scope that dying is only recognised if it is viewed as an end-of-life care experience under formal medical supervision. (2007, p251, p253)

Fundamentally, then, as Kellehear concludes in his "review of debates on the determination of death" (echoing Scarre's comments on "dying"): "Death is not decided by appeals to biology but by a social mix of medical, legal and family consensus" (2008, p1540) Which is all to say, simply, that dying is a social process

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[22] For Sassower and Grodin (1986), the very question "is the patient dead?" comes laden with complexities and can only be adequately answered with full knowledge of who is asking it, why they want to know and the evidence behind any reasoning.

[23] Equally, such institutions may act from coldly rational and clinical positions. See for example Noys on how a committee at Harvard University in 1968 determined the definition of "brain death" (2005, p57-59)

and the person cannot be untethered from the biological process, despite attempts by medicine to mechanically manage this. The consequence of treating it otherwise is terrible and two-fold, impacting everybody. By sidelining the social, psychological and existential facets of the dying individual – the very things which ensure their individuality – great distances are created between beings, severing interpersonal connections. As Louise Harmon tragically captured, even medical professionals can cut off interactions with the dying individual: "[doctors and nurses] distance themselves; they express anger at the patient; they limit conversations; they avoid contact altogether. [...] The effect on the dying person can be devastating. The abject loneliness of the situation, the depersonalization, and the denial of any kind of significant social role are forms of social death" (1998, pp125–6). I will return to this loneliness below.

The "perceptual world of the living" presently serves to render such behaviour normative. However, "dying" wasn't always under the aegis of institutional regulation. Indeed, as we shall see, dying was at one time understood to be a profoundly personal journey that happened *after* death not before it (Kellehear, 2007). Moreover, for Julie-Marie Strange (2009, p143), "meanings attached to dying are not fixed in particular periods". The trajectory "out of the perceptual world of the living" described by Benjamin – and myself – is, of course, quite specific to the West. Crucially, too, it ignores communities (and countries, such as Spain) where the dying individual dwells in a far more familiar manner amidst their fellow citizens. As such, the "perceptual world of the living" I will be describing is not a universal paradigm, but rather a theoretical conceit, deployed by way of defining the structures that currently govern how the dying individual is encountered in the West. Firstly, however, I need to establish much more concretely the history of how the dying individual has been encountered in the West, through which to make the constructed artifice – and emptiness – of the contemporary encounter even more transparent.

Several scholars have sought to trace the Western history of death. However, as Strange observes, “this literature tends to relate to understanding rites of passage regarding death and separation, in particular, grief and mourning”, adding that “the history of dying in its own right is still relatively recent” (2009, p123). Such a sentiment is possibly equally applicable to the study of death in the humanities as a whole, where – perhaps indicative of the influence of psychoanalysis – scholars have tended to concentrate on mourning and loss, rather than dying.[24] The specific subject of dying has also been under studied. As Allan Kellehear recently commented, introducing an edited collection which sought to bring together contemporary work in the field, dying “has continued to struggle to attract researchers over the years” (2009, p1).

By far the most significant intervention was made by French academic Philippe Ariès, described by Roy Porter as “the doyen of the historians of death” (1982, 335). John Tercier, writing in 2005, observed that although Ariès’s very influential history has been much criticised since its publication, “it is in its broad sweep, in most authors’ opinions, valid” (2005, p11). Ariès’s account of “Western attitudes towards death” across the past millennium was first expressed at a 1974 lecture series at John Hopkins University before the publication of his tome *The Hour of Our Death* (1981). The arc of Ariès’s thousand-year history traces the transitions from what he terms the “tame death” of medieval times to the “wild death” of today. For Ariès, the past millennium can be broken into five distinct historical modes which he

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[24] This is also perhaps a consequence of the interest figures like Jacques Derrida and Judith Butler have taken in mourning, ensuring the centrality of it to contemporary study. See for example Derrida (1995) and Butler (2004).

terms: “the tame death”, “the death of the self”, “remote and imminent death”, “the death of the other” and “the invisible death”.[25]

The “tame death” (or “tamed death”) spans a vast period, and represents a “domesticated” form of dying marked by two central components: “familiar simplicity” and the “public aspect” of one’s passing (1980, p28, 18). Significant shifts began to occur in the sixteenth, and particularly seventeenth, century, as the West transitioned to what Ariès terms “the death of the self”. The critical change involved the deathbed becoming a site upon which one’s life was summed up: a “good” death was a mark of a person’s moral character and could redeem misdeeds in life. The deathbed also became the subject of many moral and religious treatise, which “enlarged on the pain and delirium of the death agony, presenting the moment of death as a struggle of spiritual powers in which the individual was in a position to gain or lose everything” (1981, p298). Equally and theologically, the “living” began to separate themselves from the dead. Whereas there had been a belief that the two planes of existence were in many respects coterminous, death now came to be a fundamental end, with prayers or other efforts by the living having little or no effect on the fate of the dead.

Ariès’s third period – “the remote and imminent death” – marks the start of what he terms “death untamed”. The major marker of this transition was Enlightenment thinking which undermined religious understanding and dominance over death (both the rituals around it and the promise of an afterlife). Consequently, it came to be understood through rational and scientific lenses, with medicine – not least opiates – able to alleviate deathbed suffering and also precipitate a swifter end. It is now, argues Ariès, that “the great fear of death” arose. Anxiety about death became “so

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[25] This is an expansion of his original formulation, which only involved four modes missing out the “remote and imminent death” Ariès sees as a distinct stage during the Enlightenment period. On the two versions, see Porter (1998).

formidable that [people] were tempted to push it out of sight, run away from it, act as it did not exist, or falsify its appearances" (1981, p405). This led straight to "the age of the beautiful death" (*ibid*, pp409-474) – the romanticised Victorian vision of a deathbed, in a private chamber, where the dying individual – peaceful, dignified and solemn – says their goodbyes, perhaps offers some parting words of wisdom, and then slides off into a sleep from which they will never wake. Ariès suggests that: "Presence at the deathbed in the nineteenth century is more than a customary participation in a social ritual; *it is an opportunity to witness a spectacle that is both comforting and exalting* (1981, p473; emphasis mine). I emphasise this sentence because, as we will come to see, a similar spectacle of dying is offered to contemporary spectators through film and television.

The tranquil, managed, passage towards death observed in such deathbed scenes would eventually give rise to a wish "to protect the dying or the invalid from his own emotions by concealing the seriousness of his condition until the end" (1981, p612). Accordingly, the modern medical institution, and the rationality of scientific discourse within, offered a site where "emotions would be banished" (*ibid.*). This passage was precipitated too by the perception of death as "dirty", of the dying individual as a spreader of disease. Moreover, death "ceased to be accepted as a natural, necessary phenomenon", but instead was regarded as "a failure" (p586). The once communal encounter with death thus slowly eroded to a state of social, cultural and psychological denial, transforming death from a public to a highly private affair, with grief and mourning increasingly seen as indecent acts. Whereas dying had, for Ariès, in varying ways previously been integrated within the human and communal experience, modern society, he argues, "has banished death" (p560).

Allan Kellehear's *A Social History of Dying* (2007) offers a useful counterpoint to Ariès's work, firstly with respect to historical breadth and secondly concerning sociological scope. Kellehear starts his survey far earlier that Ariès does, finding a rather startling possibility in the process: "a lot of 'dying' occurs in [the Stone Age] as a process that follows death rather than preceding it" (p24). Dying thousands of years ago was typically sudden, often very violent and came with little warning. Humans believed that the dead then went on an often arduous "otherworld journey", which the literature suggests was regarded as "a dramatic, even spectacular journey to an often surreal if uncertain destination" (p43). For Kellehear, Ariès's omission of "dying as otherworld journey" – our longest tradition of dying – skewed his analysis.

Kellehear especially critiques Ariès's exclusion of the experiences of poorer classes, relying instead upon the records and texts of "a privileged elite", to develop his account of the "tame death" (pp172-181).[26] He suggests that:

> From the very literature that Ariès employs to show how death was once tame we can see equal evidence, if we view this literature as political artifice by vested interests of the day, that elites were requiring detailed reminders and reassurances that death really could be tame for them. (2007, pp178-179)

Kellehear contends that the "literary and religious accounts of dying" used by Ariès "are not ethnographic portrayals of dying scenes but moral devices", intended to tame "personal anxieties about the physical, emotional and spiritual crisis of dying" (p174). For Kellehear then, in the period of Ariès's "tame death" there is ample

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[26] Indeed, as Strange (2008, p142) notes, "there is relatively little historiography that engages at length with the dying experiences of diverse ethnic and confessional groups [...] or the poor."

evidence that death had in fact "already become 'wild' in the minds of the educated and largely urban readers of those times" (*ibid.*). Moreover, by missing out "dying as otherworld journey", Ariès fails to grasp a crucial historical shift, namely the fact that:

> Death became wild, not because doctors, lawyers or hospitals appeared on the scene but because the old place of death (the afterlife) became questionable, even evaporated before the eyes of an increasingly skeptical urban elite. (1981, p177)

We see, then, instead of a "tame death", increasing attempts at "taming" what is rapidly becoming a "wild death". For Kellehear, this can be understood as an attempt at "managing" dying to produce the "good death"[27]. This preoccupation with management was historically the concern of the wealthy, urban classes, leading to the incredible professionalisation of death in the nineteenth-century intended to assuage bourgeois anxieties about the indignity of suffering and concerns over the loss of material possessions (pp143-145). For everybody else, dying was a much more natural occurrence, in part because economics dictated living conditions in which death was by necessity a shared, social, interpersonal experience.

With modernity came fundamental changes in social structures. Particularly pronounced was the growing efficacy and availability of public healthcare: infant mortality figures radically decreased, childbirth became safe, the tide of viral deaths was stemmed and, as now, life expectancy rose. Encouraged through regulation and legislation (which, for example, meant that individuals dying of disease were

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[27] See also Conway (2007) for discussion of the shifting ways the "good death" has been understood in modern times.

"removed to hospitals on warrant") the "managed death" became the model for all (pp201-202). This gave way to not just "an erosion of awareness of dying" but, perhaps more significantly, "an erosion of support for dying" (p210, p210). This is compounded by contemporary longevity, itself buttressed by medical technology, whereby an individual's biological dying can be a long, extended, process. A person's "social death", which Kellehear defines as an individual's perceived "interpersonal irrelevancy, uninterest or even rejection by others", can occur much earlier (p237). Indeed, the contemporary isolation of the dying individual is, for Kellehear, a consequence of the fact that "dying has become a form of social death" (p246).[28]

Kellehear considers the conditions of the "tame death" as constituting "a place populated with beings, customs, moral codes, and above all, social order" (p177), in contrast, that is, to a "wild" death which unsettles by being untethered from explanatory narrative, ritual, familial and community bonds. In the terms currently under discussion, we can thus see "taming" (or "managing") dying as the function performed by the "perceptual world of the living". Over time, the "perceptual world of the living" permitted professionals and institutions to take control of dying away from the communal fold. Accordingly, dying – and moreover, the dying individual – became increasingly alien from the community and absent from the public sphere. Crucial to this transition was the rise of moral frameworks structuring understandings of dying: the discourses that constitute the shared understanding of

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[28] Complimenting Kellehear's class-based observations Ivan Illich (*) offered a staunch, early, critique of the unnecessary and dehumanising medicalisation of dying, within a broader thesis attacking what he regarded as medicine's attempts "to engineer the dreams of reason" (1977, p47). Illich highlighted the role individual wealth plays [0]in one's experience of death: "Privilege or poverty in earlier life reaches a climax in modern old age. Only the very rich and the very independent can choose to avoid that medicalisation of the end to which the poor must submit and which becomes increasingly intense and universal as the society they live in becomes richer" (p92).

(*) Not to be confused with the protagonist of Tolstoy's novella *The Death of Ivan Ilyich*.

the "good death".

Whilst the "good death" may, today, be thought of in opposition to a "bad" institutional, isolated and painful death, it was historically understood in moralistic and religious terms: a spiritual rather than physical dictate. For example, as Strange explains, "bad deaths most commonly referred to deaths that were deliberately unchristian, such as the death of an atheist or unrepentant sinner" (2009, p132). The more that dying was managed, the less the dying individual was accorded agency, as they were obliged "to comply with religious and social expectations", following the current "cultural script for dying" (p138).[29]

Today's "cultural scripts" on what constitutes a "good death" stem from society's escalating unfamiliarity with actual dying. Moreover, their contours are drawn from cultural (and fictional) projections. Author and cartoonist Ross Mackintosh captures this well in a passage in *Seeds*, a graphic novel about his father's dying:

> "Okay, maybe he is dying," I told myself, "but it won't be one of those undignified deaths. They'll be no shitting himself or shuffling around a hospice. He'll die with grace ... like they do in films." (2011, p12)

In contrast, the reality for family onlookers is often marked by their gross unfamiliarity and unpreparedness for what can occur. Likewise, what they learn might be deeply unsettling.[30] In 1993 Dr Sherwin Nuland was moved to write *How*

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[29] Strange also makes the pertinent observation that "forms of dying that were explicitly public [...] were usually classed as 'bad' deaths" (2009, p137). Strange's comments are chiefly regarding violent deaths – such as fatal accidents or public executions – however perceiving dying in public as "bad" would come to encompass natural death.

[30] For example, Laurie Ross writes of the moment a surgeon confirmed how her father, riddled with abdominal cancer, would die unless they fitted a colostomy bag: "He would without question [...] vomit his own fecal matter until the moment of death" (2011, p17).

We Die: Reflections on Life's Final Chapter precisely to demystify the actualities and banalities of what happens in the final months, weeks and days of one's life. Nuland poignantly reflects on his professional experience:

> How often have I stood with families at a deathbed and witnessed their disbelief at this process unfolding its too-often-agonizing panorama before them. They question why it is different from their expectation and why seemingly they alone should have to endure what they conceive to be a uniqueness of suffering. (1993, p62).

Missing in the dynamic Nuland describes is the perspective of the dying individual. The "suffering" described is that of the survivors. This will come to be a critical point. The greater the "invisibility" of dying, the greater impact cultural texts that represent it have. And those texts, almost exclusively (especially visual ones) are the product of the still "living", trying to make sense of a fate they have yet, themselves, to face.

Norbert Elias sought to think through much of the above from the perspective of the dying individual. His 1985 book *The Loneliness of the Dying* is infused with a particularly personal resonance, as it was written when Elias was in his eighties. Loneliness, for Elias, is not simply literal isolation, whether personal or institutional, but the sense of suddenly becoming a socially worthless individual, cast out from the "living". He sees this partly as a result of historic shifts which emphasised the role of the individual self over that of the group. Whilst his approach has universal overtones, Elias notes throughout that he is generally describing the situation in developed countries. Indeed, he identifies the modern isolation of the dying individual as a consequence of the Western tradition, particularly that fostered by industrialisation. For Elias, an understanding of the necessary dependence of people on others to instill meaning and value has increasingly escaped social consideration. He regards interdependence as:

> particularly impeded today by the refusal to look the finitude of individual life, including one's own, and the coming dissolution of one's own person, directly in the face, and to include this knowledge in the way one lives one's life – in one's work, one's pleasure, and above all in one's behaviour towards others.
>
> Too often, people today see themselves as isolated individuals totally independent of others. (1985, p34)

Such a sentiment is echoed by Kellehear who suggests that a consequence of the contemporary *status quo* means that the dying individual "might be the *only* one aware that he or she is dying" (2007, p251; emphasis in original).

Elias argues that dying produces barriers to empathy because they present physical and psychological states that others do not just *struggle* to imagine, but do not want to imagine.[31] The bodily difference of dying is often considered "a deviation from the social norm" (p69), which encourages institutionalisation as a means of comprehension and containment. Equally, through reducing the dying individual to a body in need of clinical care and isolating them from communal view, society can more easily ignore their very real need for personal and physical support. As Elias observes: "[i]t is perhaps not yet quite superfluous to say that care for people sometimes lags behind the care for their organs" (p91). Grof and Halifax

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[31] This is reminiscent of Sigmund Freud's frequently quoted claim, suggesting that individuals are unable to conceptualise their own dying: "We cannot, indeed, imagine our own death: whenever we try to do so we find that we survive ourselves as spectators" (1918, p41).

(1978) illustrate the institutionalised severing of interdependence well when they observe that "the companions of many dying individuals are infusion bottles and tubes, oxygen tanks, electric pacemakers" (p7). Likewise, after interviewing many dying patients, psychologist Elizabeth Kübler-Ross summarised the tragic human consequences: "He may cry for rest, peace, and dignity, but he will get infusions, transfusions, a heart machine, or tracheotomy if necessary" (1969, p9)

Family, friends and professionals can be complicit in the "loneliness of the dying". Indeed, as Michel de Certeau suggests, when somebody vocalises the statement "I am dying", they may be greeted with fictions such as, "of course not; you're going to get better". This lie, de Certeau argues, is "a way of assuring that communication will not occur" (1988, p190). Heiner Schmitz, a 52-year old hospice patient interviewed in 2003 by photographer Walter Schels and Beate Lakotta, poignantly articulated his sense of isolation and how his interpersonal connectedness with others has been severed:

> No one asks me how I feel. Because they're all shit scared. I find it really upsetting the way they desperately avoid the subject, talking about all sorts of other things. Don't they get it? I'm going to die! That's all I think about, every second when I'm on my own.[32]

Similarly, Charles Leadbeater recalls that during his father's final weeks in 2010, "no one was comfortable talking about the fact he was dying", an observation which encompasses the health professionals assigned to care for him in hospital (2010,

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[32] Quoted on *lens culture* website: http://www.lensculture.com/schels.html [Accessed September 28th, 2012]

p6).[33] The willingness to foreclose communication can be considered in relation to "death anxiety": the self's reluctance to entertain questions of its own finitude (see especially Becker, 1973; Yallom, 1980; Piven, 2004). Robert Jay Lifton speaks of this as "the universal human fear of death without integrity – of a death that is disintegrative in its humiliation, incoherence, absurdity, or prematurity". He adds: "To imagine such a death is to see one's life in the same terms" (1980, pp100–101).

Psychotherapist Irvin Yalom sees the fear of death as playing "a major role in our internal experience [that] haunts as does nothing else" (1980, p27).[34] Building on the work of Otto Rank, via Ernest Becker (1973), Yalom finds the repression – or rather, the denial – of death leading to the restriction of life. Rank saw man as existing in a state of push-and-pull, between a movement against life, which culminates in collectivity and disintegration, and a movement against death, which culminates in individuality and isolation. It is in incorporating these twin pillars of life and death into the mental everyday that leads to a richer existence; "although the *physicality* of death destroys man, the *idea* of death saves him" (1980, p30). Yalom contends that in practical terms, man is constrained – as a result of the defense mechanisms he has erected – from fully embracing life. This is not a wishy-washy sentiment, but based on the contrast with people who have, in as much as is healthily possible, overcome their own death anxiety, keeping death awareness as a component of their consciousness (pp33-40, pp159-217; also Yalom, 2008). Equally, this isn't a recipe for hedonism, but rather a "reassessment of priorities" which often leads to one "becoming more compassionate and more human

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[33] In Leadbeater and Garber (2010, p6). One suggested reason for health professionals' – particularly doctors' – struggles with communication is, as Janet Berman writes, the fact that the dying individaul "confront[s] the physicians with his or her own helplessness, with tangible proof of professional 'failure' and the limitations of medicine" (1991, p49).

[34] Yalom finds the extent of death's denial vast. Indeed, it doesn't even "spare the therapist," with Freud having a "persistent blind spot" over his own "avoidance of death" (pp59–74).

orientated" (p34). Unfortunately, as Yalom observes, this tends to be achieved in the wake of a near-death experience or within the process of a terminal illness.[35]

Zygmunt Bauman (1992) argues that death posed a specific problem to the West. For Bauman, "death is the absolute *other* of being, an *unimaginable* other" (1992, p2), which rendered it "the ultimate challenge to the modern ambition to transcend all limits" (1995, p168). As such, it was "decomposed" into physical diseases and conditions which, at a minimum, could be identified; at best, halted. Death, then, was the one thing that modernity couldn't master and so social structures responded by giving citizens a false sense of invincibility and immortality by keeping dying out of sight and out of mind. Michael Kearl calls this "the social shock absorbers of death", noting the varying "structural mechanisms" and "institutional strategies" Western society employs to "minimize death's disruptiveness" (1989, p93). Such structures and strategies, of course, are the mechanics of "the perceptual world of the living".

Bauman and Kearl's observations are supported by Phillip Mellor, who draws on Anthony Gidddens' (1991) notion of "ontological security": the self's wish for meaningfulness, stability and continuity in everyday experiences and encounters. Mellor (1993) argues that since modernity, Western society has structured itself to minimise, perhaps eradicate, threats to our "ontological security", not least reminders that we, ourselves, will one day die. Furthermore, as Jackie Stacey (1997, p9) states, "we are encouraged to think of our lives as coherent stories of success, progress and movement". Accordingly, the autobiographical impasse of dying, let

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[35] For example, Philip Gould (2012), writing with weeks to live, spoke of "surging forward and growing at a pace that I have never experienced before" (p133). He adds, capturing a transition from individualism to interdependence, "I am trying to make sense of the world not through time but through emotion, through relationship, through feeling" (p134). Similarly, Anatole Broyard wrote in his journal the month before his death: "Why did all this wisdom and beauty have to come so late?" (1992, p68).

alone the personal uncertainties of illness, presents a specific challenge to the self. Indeed, the possibility, or rather reality, of our finitude is perhaps the ontological challenge *par excellence*. The dying individual, their interdependence with fellow citizens severed, is ever left to their own devices, or rather abandoned to their fate.

What is lost as a consequence? Here, we can return to Ariès who rhetorically asked: "But how are we to explain the abdication of the community?"

> The answer is that the community feels less and less involved in the death of one of its members. First, because it no longer feels it necessary to defend itself against a nature which has been domesticated once and for all by the advance of technology, especially medical technology. Next, because it no longer has a sufficient sense of solidarity; it has actually abandoned responsibility for the organisation of collective life. (1981, pp612–3)[36]

In striving to avoid death, Western citizens increasingly curtailed their communal connections, choosing instead to pursue individual paths. To keep the threat of finitude at bay, the dying individual was bracketed away from "living" and pushed out of the public sphere. Over time, this came to take on a normative tenor. As Kearl suggests, "only when our cultural death-denial system is punctured do we have a glimpse of the chaos posed by death and for many even the glimpse can destroy the complacency and security they have in the social order" (1989, p71). Indeed, this is how the images of Barb Tarbox and David Kirby dying are immediately seized as shocking, rather than everyday (if, of course, tragic) sights.

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[36] Relatedly, Alphonso Lingis poetically argues: "Community forms in a movement by which one exposes oneself to the other, to forces and powers outside oneself, to death and to the others who die" (1994, p12). See also Gibson (2011)

The perceptual world of the living constructs "them" as different from "us".

Dying has thus become a form of "social death" because it is understood as opposite to "living", rather than a process within it (see Scarre, 2009). The perceptual world of the living conspires to make this so. There is, as Elias observed, "a peculiar embarrassment felt by the living in the presence of dying people" (1985, p23). We can perhaps see now why Kellehear (2007) categorises contemporary dying as the "shameful death", a shame sadly felt much more by the dying individual than by society.

Writing for *The Sunday Times* in 1972, Germaine Greer observed, "death has never been so mysterious, so obscene or shameful an occupation as it is in our time" (1987, p146). However, beginning in the 1960s, a raft of books appeared, the popularity of which began to suggest that the "final taboo" of death was lifting, if not entirely overcome. The texts, emerging concurrently with critiques in the professional presses, spanned the social, psychological and historical aspects of death.[37] Indeed, between 1979 and 1987, Michael Simpson was able to extend his

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[37] They include Jacques Choron's *Death and Western Thought* (1963), Jessica Mitford's bestselling 1963 critique of the funeral industry *The American Way of Death*, Elizabeth Kübler-Ross's hugely influential *On Death & Dying* (1969), Philip Ariès's aforementioned *Western Attitudes Towards Death* (1974) and Ernest Becker's very popular *The Denial of Death* (1973).

As well as these, other mainstream publications include Geoffrey Gorer's *Death, Grief and Mourning in contemporary Britain* (1965); Al Alvarez's *The Savage God: A Study of Suicide* (1971/2002); Robert Jay Lifton and Eric Olson's *Living and Dying* (1974), Colin Murray Parkes' *Bereavement* (1975); John Hinton's *Dying* (1972); Edwin S. Shneidman's *Deaths of Man* (1974); David Cole Gordon's *Overcoming the Fear of Death* (1972) and two other books by Elizabeth Kübler-Ross, *Questions and Answers on Death & Dying* (1972) and *Death: The Final Stages of Growth* (1974).

Also significant at this time was Barney Glaser and Anselm Strauss's groundbreaking ethnographical studies of dying in American hospitals, *Awareness of Dying* (1965) and *Time For Dying* (1968); Ivan Illich's critique of medical institutions, especially regarding dying *Limits to Medicine* (1976), as well as the writings of Cicely Saunders (2006), regarded by many as the founder of the modern hospice movement.

Concurrently, there also appeared non-fiction narratives written by family and friends of loved ones recounting the story of their dying, perhaps precipitated by Simone de Beauvoir's memoir of her mother's passing, *A Very Easy Death* (1965).

bibliography of “death and dying” by some 1700 books.[38] Such a state of affairs led Tony Walter, in 1994, to “wonder whether we are witnessing a revival of death” (p1). Walter (1991, 1994, 2009) also raises necessary questions around whether the West *has* witnessed significant shifts in the past two decades and the extent to which certain intellectual discourses are failing to describe what is actually happening. Is death really still “taboo” and can we realistically speak of a “denial of death”? Indeed, is death actually still “sequestered” in contemporary society?

A central problematic is that these notions were first forged when it was necessary to use broad and strong language to describe realities which had become imperceptible. Today, they have become too loose, too unspecific and too easy to (incorrectly) reject. Firstly, “death” is far too wide-reaching a phenomenon and too imprecise a term to fall under a blanket “taboo”, especially today. The prevalence of death in our daily news media – in stories of murder, natural disaster, violent conflicts, or the passing of a public figure – clearly indicates a readiness to engage with mortality, albeit in certain ways.[39] Taboos around death are now much more subtle and much more specific to dying. Secondly, the meaning of “denial of death” or “death-denying” is slippery: the psychological definition of “denial”, describing a defense mechanism, gets stripped of some of its significance when the term is used in broader discourse. Moreover, it fails to fully capture whether that denial is actually working and precisely what – and crucially whose – death is being denied.

I argue that the perceptual world of the living presently encourages citizens to deny the actualities of dying – and the actual dying of others – whilst also giving

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[38] Observed by Tony Walter (1994, p1) referring to Simpson (1987). It should be noted, though, that even Ariès observed in 1974 that “death is once again becoming something one can talk about” (1976, p103).

[39] Anecdotally, too, I have found people incredibly willing to talk about death and dying *once they feel they have been given permission to do so*. After speaking about my research, people – sometimes complete strangers to me – have often shared the most intimate stories about family and friends who have died.

citizens the means to imagine a “good” (and “beautiful” and “meaningful”) death for themselves. The “denial of death” thesis also lends itself to a ready and oversimplified corrective: if the West could reach (once again) greater acceptance of death, the life of the dying and their survivors would be much improved. As Jonathan Dollimore pointedly remarks, the “hope for a healthy attitude to death and loss is on occasions [...] so trite that it could itself be blatantly symptomatic of the denial of death, being apparently incapable of acknowledging on the personal level just how devastating and unendurable death is” (1998, p123). Adding to this problematic, Camilla Zimmerman and Gary Rodin (2004) capture well what gets forgotten in claims that a social “acceptance” of death would bring major changes: the need to change “the material conditions that the dying and those caring for them have to face” (p127). This will come to be a crucial point in the following chapter when I consider reforms in end of life care.

Through institutionalisation, medicalisation and social exclusion, the encounter with the dying individual became increasingly foreclosed and screened away from public view. This sequestration and severing of intersubjective engagement was further reinforced by barriers of taboo. However, within the “perceptual world of the living”, the dying individual is screened *for* public view through visual culture. This matters. For example, in the United Kingdom today it is increasingly common for citizens to reach their fifties before experiencing an actual dying situation (NHS West Midlands, 2009, p6). Therefore, as Margaret Gibson argues, “death is not known by experience but by [...] its dissemination through mass media” (2011, p19).

Already, we can see a conflict with the notion that contemporary death has been rendered "invisible". Indeed, as Sandra Gilbert asked: "How [can we] reconcile death denial with death display?" (2007, p229). We can perhaps consider representations of the dying individual in visual culture in terms of what psychologists Robert Jay Lifton and Eric Olson (1974) call "death imagery". This is ostensibly a buffer against the threat – and reality – of mortality, alongside the fear of physical disintegration, the sentience of which can be unsettling across all ages. Western society's increasing estrangement from actual death has meant that culturally produced discourse has increasingly been providing the paradigms, morals, aesthetics and tropes from where we form our death imagery. As Sara Knox (2006, p234) suggests, citing Berridge (2001, p7):

> if "the fear of death is chiefly performance anxiety about dying" then the only cure for morbid self-consciousness is rehearsal, yet all that can be rehearsed is one's reaction to the death of others or the fantasy of immortality.

Fundamentally, then, I suggest the encounter with the dying individual in visual culture typically produces the same dynamic as in the social sphere: the securing of the spectator's "ontological security". Whilst society strives to keep the actualities of dying out of sight, visual culture provides "cultural scripts" which offer false reassurances.

Firstly, it is necessary to note that little has been written on the topic of contemporary representations of dying. What exists is partial and fragmented. Where discussions of death in visual culture exist, they typically focus on violent death, or on mourning and loss. Furthermore, historians, sociologists and other scholars of dying typically omit visual texts from their studies. Ariès integrates visual culture by far the most into his work (1976, 1981), even publishing a separate book on *Images of Man and Death* (1985). Tony Walter has also written on Jade Goody's very public dying as presenting a possible challenge to the "sequestration" theory of death (2009, 2010).[40] Clare Gittings (2007) offers a broad overview of the "art of dying", whilst Chris Townsend's *Art and Death* (2008) tackles the topic through a largely theoretical lens, and is chiefly concerned with contemporary artists. Audrey Linkman's *Photography and Death* (2011) is mostly focused on dead bodies and postmortem photography. Laura Tanner (2006) considers gaze theory in relation to terminal illness. Her chapter on photographs depicting citizens with AIDS is complemented by David Campbell's work (2008). Bertman's *Facing Death* (1991) examines the role visual culture has played – and can play – in educating citizens about death. Sandra Gilbert (2007, esp. pp204-241) discusses some representations of dying in the context of her wider cultural study on death. Charlton Mcllwain's *When Death Goes Pop* (2005) looks at contemporary popular culture, particularly television, although without much attention paid to dying itself. John Tercier's *The Contemporary Deathbed* (2005) is perhaps the most focused and remarkable work on popular culture and dying and will be discussed further below.[41]

Work on death and dying in film is, given its frequency in the medium, surprisingly slim, with no comprehensive texts, however see Michele Aaron's forthcoming *Death and the Moving Image: Ideology, Iconography and I.*

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[40] See also Woodthorpe (2010) and the discussion in Chapter 3 of this thesis.

[41] Tercier, a doctor and cultural historian, focuses closely on cardiopulmonary resuscitation (CPR). He finds that its longevity in hospitals, long after better methods were discovered, as well as its application on dying patients, even when it would be futile to do so, has been shaped by society's deep underlying fear and anger towards death. Moreover, CPR's repeated presence in film and television has reinforced its perceived correctness against better medical judgment.

Scholarship has been also rather scattered across disciplines and approaches with most focus on violent death, for example Grønstad (2008), Oeler (2009) and Hagin (2010). Fran McInerney offers possibly the only survey of terminal illness in film (2009), however her chapter doesn't engage with wider scholarship in film or media studies. Similarly, discussions of individual films, such as Peggy Phelan's (1997) article on documentary *Silverlake Life* (1993), are typically removed from other academic work in death studies. Catherine Russell's *Narrative Morality* looks at death in New Wave cinemas, whilst Emma Wilson's recent (2012) book focuses largely on mourning in various auteurist directors works. bell hooks (n.d.) reflects on the commercial and "racial politics" at play in mainstream melodramas about dying. Vivian Sobchack's influential essay (2004)[42] on spectatorship, death and ethics has led to several articles and books which examine the subject through shared concerns, such as Gibson (2001), Davis (2004), Knox (2006) and Tait (2009). The main focus for all, however, remains violent rather than natural death.

In 1965, Geoffrey Gorer set forth a thesis that still shapes discussion on the subject today. Gorer argued that "death has become more and more 'unmentionable' *as a natural* process" (1995, p20, emphasis in original). He suggested that this was a consequence of people's increasingly unfamiliarity with dying. Gorer posits that whilst "the natural processes of corruption and decay [had] become disgusting", there occurred a corresponding escalation in "violent death" through wars, genocides and, closer to home, the traffic accident. As a result, "violent death has played an ever growing part in the fantasies offered to mass audiences"; a sort of return of the repressed. Gorer called this a "pornography of death", arguing that it

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[42] First published in 1984, Sobchack's essay 'Inscribing Ethical Space: Ten Propositions on Death, Representation and Documentary,' was republished within her 2004 collection of articles *Carnal Thoughts* (pp226-257).

"titillates" its audience, serving only individual "gratification" and thus ultimately seeking "the complete hallucination of the [...] viewer as [its] object" (pp20-21, p22).[43] Accordingly, the spectacle of death came to displace the natural actualities of illness and the everyday banalities of dying.

Vicki Goldberg (1998) agrees with Gorer's claims, adding that the "pornography of death" he observed was "not new, only larger and bolder". Goldberg looks to nineteenth century visual culture and finds that death and dying was "gradually becoming more mediated than immediate" (p31), with imagery reframing the everyday encounter with death. Meanwhile, news media, with an escalating sensationalism, offered increasingly graphic illustrations of violence and death, whilst early cinema "laid claim to a more extensive and intimate view of death" (p49). Goldberg concludes:

> Images began to fill in, to substitute, to heighten the terror and often, at the same time, to calm the nerves by their sheer improbability, over a century before Gorer wrote. They began their dance with death long before that, but they hit their stride almost as soon as mass reproduction and a mass audience began to take shape, at the moment that death began to shift from ritual to news and entertainment. (p51)

John Tercier (2005) also concurs with Gorer, stating that little has changed in the intervening years. Whilst the majority of Western citizens die in an institutional setting, hospital dramas rarely feature "natural" death because it lacks dramatic impact, and so it is generally only encountered when the dying individual is young,

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[43] Michael Kearl compliments Gorer's idea of the "pornography of death", noting that "death becomes pornographic when abstracted from its natural human emotion, which is grief" (1989, p387).

and/or suffering from a rare, often incurable, disease. The contemporary spectator is thus accustomed to witnessing a great deal of violent death (whether real or fictional) but has minimal experience of seeing natural death. For Tercier, "fantasies of the 'good' death tend to coalesce around identifiable cultural scripts". He identifies two dominant discourses – death with dignity and "hi-tech" (i.e., medicalised) death (p10). Tercier also notes the interesting representational heritage of death. The original derivation of "obscene" comes from the Latin *obscaena*, or "off-stage", referring specifically to the absence of the actual moment of death from ancient Greek theatre. He remarks that whereas representation of death was once considered obscene, now it is death itself (p212).

The dying individual we encounter in film is thus typically fictional: an actor playing pretend. Very little has been written on terminal illness in cinema. Some individual films have received critical attention, however even that scholarship is sparse. Fran McInerney's survey of mainstream dying films concludes that they offer "little for death-quarantined Westerners other than a further estrangement from the reality of our shared destiny" (p229). I follow McInerney's sentiments, although I will discuss the limitations of her study in a subsequent chapter.

Documentary introduces reality into the equation, potentially bringing us closer to actuality and away from "fantasies of the 'good death", but I feel that documentary potentially accentuates, rather than undoes, the above observations. This is largely a question of how the encounter between spectator and dying individual is staged and mediated by the documentarian. Vivian Sobchack (2004) notes the morally charged nature of documentaries which offer direct gaze upon "natural" dying, of which there are very few.[44] For Sobchack, "as the filmmaker watches the dying, we watch the filmmaker watching and judge the nature and quality of his or her interest" (p243). I will be considering this question of *responsibility* in depth in chapters to come.

The dying individual has become so unfamiliar in everyday life that when photographed and encountered in visual culture – like Barb Tarbox or David Kirby – their image serves to shock. Such pictures puncture the public sphere simply because they capture actualities typically occluded from social view. Moreover, they unsettle the "perceptual world of the living" because they threaten "fantasies of the 'good' death", which is why the encounter is so often bounded by ideological, moral or commercial intent. Indeed, the "perceptual world of the living" ensures that the encounter between self and dying individual is always already foreclosed. This foreclosure works to inhibit interpersonal, communal, relations by denying the subjective presence of the dying individual.

Zygmunt Bauman argues that "death is the absolute *other* of being, an *unimaginable* other" (1992, p2; emphasis in original). In this chapter, I have sought to argue that dying has become falsely understood as the *other* of living. As they unsettle the modern assumption that death can be mastered, the realities of dying need to be kept at a distance. This task is performed by the "perceptual world of the living", which currently constructs the dying individual as different from the "living". Or, put another way, the "perceptual world of the living" currently offers certain securities to those who are "not-dying". Those securities are based on a pretense and trigger the "social death" of the dying individual. The role that visual

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[44] Amos Vogel's observation in 1974 that "there are so few film records of individuals dying of natural causes" (1974/2005, p263) is still a comparatively accurate sentiment nearly four decades later.

culture plays in sustaining (or reframing) the *status quo* has been seldom discussed and is the focus of the following chapters.

If our formative encounters with the dying individual take place on screen, what are the ethical and political implications of this? Moreover, what is the *responsibility* of the spectator in such a situation? Finally, can visual culture be used to challenge the *status quo* through fostering an *ethical* encounter between spectator and dying individual? These questions form the core of my enquiry moving forward. I begin by looking at a national public health project which sought to use community produced photography as a means of challenging public taboos by facilitating a “dialogue about living, dying and death”. The project, however, unintentionally (indeed, unconsciously) perpetuated existing structures that keep the encounter with the dying individual always already foreclosed. By examining how this occurred, we will lay the foundations for an ethics of spectatorship in the encounter with the dying individual.

CHAPTER TWO

UNSETTLING STRUCTURES OF OTHERNESS:

THE DYING INDIVIDUAL IN END OF LIFE CARE REFORMS

> It is indecent to let someone die in public. It is no longer acceptable for strangers to come into a room that smells of urine, sweat, and gangrene, and where the sheets are soiled. Access to this room must be forbidden, except to a few intimates capable of overcoming their disgust, or to those indispensable persons who provide certain services. A new image of death is forming, a hidden death, hidden because it is ugly and dirty.
>
> - Philippe Ariès (1981, p569)

Contemporary Western society is currently confronting a serious problem. There are not the resources – physical, financial, political or emotional – to ensure a genuine quality of life to those who are dying. Indeed, quite the reverse. People are living longer and dying longer, with the end of their life routinely occurring invisibly behind institutional walls. Citizens spend their final days, weeks and months – sometimes years – kept away from their community and even their family. Over the course of the last century, the dying became increasingly absented from the family home and the communal fold. Natural death became a medicalised event, with the hospital providing the main site for the contemporary deathbed. This excessively institutionalised response to terminal illness and gradual physical decline further stripped the subjective presence of the dying individual. Alongside these physical structures, discursive structures work to sustain the *status quo*. The "perceptual world of the living" presently ensures that the encounter with the dying individual is always already foreclosed. As such, the dying individual is objectified, stigmatised and contained within a framework that keeps them at a distance – as other – from their fellow citizens.

Recognition of the necessity for correctives has occupied multidisciplinary and professional discussion of death and dying for some years.[45] In this chapter I will consider the above issues through the lens of contemporary Western end of life care reforms: the efforts by public health authorities to substantially improve the ability of individuals to experience death in a manner and a place of their choosing. Specifically, I will consider a project run by the British National Health Service (NHS) in 2009, which culminated in a three-day exhibition in the city of Birmingham. Entitled “Saying the Unsayable: Opening a dialogue about living, dying and death”, the exhibition was run as part of a national strategy which is seeking to fundamentally reform British citizens’ experience of dying. It displayed around one hundred photographs, selected from over eight thousand images taken by a range of community groups in and around Birmingham. These were complimented by a short documentary, interactive theatrical performances, a glossy guidebook and other materials.

On the last day of the exhibition, a passing group of Sudanese citizens stopped by. They had been attending a local conference and were curious about what they saw. Key to their intrigue was a central question: Why do British citizens have such difficulty supporting those who are dying, when surely this should be part and parcel of human nature? This intervention, by individuals viewing the exhibition from a perspective outside British – nay, Western – paradigms, lays the foundation for what follows. What are the structures which frame “our” encounter with the dying individual and how can end–of–life care reforms best work to puncture them?

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[45] See the proceeding chapter, also especially Kellehear (2005), Saunders (2006), Sinclair (2007), Leadbeater and Garber (2010). For a popular account, see Stephen Kiernan’s *Last Rights: Rescuing the End of Life from the Medical System* (2006).

Moreover, how can these reforms ensure that the dying individual is not simply returned to "the perceptual world of the living", but welcomed there as a citizen amongst equals? I will argue that the dying individual was unintentionally – indeed unconsciously – the structuring absence of the exhibition. As such, I suggest that it replicated certain problematic structures of otherness. I argue further that if end of life care reforms are to succeed in treating all citizens equally, physical *and* discursive structures of otherness must be identified and unsettled.

By way of an example of how end of life care reforms can be well intentioned, but problematic, I want to briefly discuss a recent film. *Dying to Know* (2012) was produced by *Dying Matters*, a government funded organization formed in 2009 **"**to promote public awareness of dying, death and bereavement".[46] The thirty-minute film, adapted from a play by Helen Reading, is the latest in a series of short films made by *Dying Matters* intended to act as tools for discussion and reflection for both public and professional audiences. *Dying to Know* is, however, their most elaborate and lengthy production to date and played at the 2012 Cannes Film Festival. Filmed on the Isle of Wight, it examines the family dynamics between Helen, who is dying, her daughter Jane and grandson Sam.

From the film's opening, Helen talks and jokes about dying and having to do "all the usual end of life tasks". However, many of her conversations are held with her husband Rod, whom we quickly discover is dead. Rod appears throughout the film in the form of a ghost, or projection of Helen's imagination, offering support, familiarity and solidarity to his wife. The central drama is less Helen's dying and instead Jane's difficulty in trying to have an open and frank conversation about

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[46] *Dying Matters* "About us" website page: http://www.dyingmatters.org/overview/about-us [Accessed September 28th, 2012]

Helen's end of life wishes. Jane kept her distance when her father, Rod, was dying and this apparently triggered a family rift. She articulates her main worry to her son Sam, "do I look after Gran and nurse her, or do I step back and let her have her independence?" The dramatic resolution comes with mother and daughter sat sharing a tender moment on a bench overlooking the sea. With the two women stoic and staring seaward, pointedly avoiding each others' gaze, Jane finally asks, bluntly: "Ready to talk?" In her response, Helen recollects a film she once saw about "a man dying" who said: "treat my death as if it was your own". She says that's how she thought about her husband's dying and that's how she'd advice her daughter to approach it. Through tears, Jane offers her own wishes, which are very much wedded to the notion of the "good death". She says, "I'd want to be at home, with my family and stuff around me". Then, with a small laugh, adds, "and someone to come in and have to wash my hair every day".

The conversation continues and then the two women exchange deep embraces against a solemn soundtrack [fig. 6]. The film then transitions – through a burst of white light – to an imaginary space. Helen is alone on a boat, with otherworldly fog swirling around her. A similar transition then takes us to the reality of Helen's deathbed, where she lies immobile, framed on either side by Jane and Sam, sat holding her hands. As the camera moves gently in towards her face, another burst of white light comes through returning us to the boat.[47] Helen is leaning on a railing, gazing out at the bright sun on the horizon. The inference is that as her body lays dying, she herself is here, on her final journey, contemplative and alone. This cycle of transitions repeats until a figure – her husband, Rod – greets her with a gentle hand on Helen's shoulder. She looks up, pensive, as the film's brightly saturated

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[47] The fade-to-white and similar transitions are often used in film to invoke death. See for example *My Life* (1992) and *Things Fall Apart* (2011).

colours slide into a natural palette, an effect repeated in a second, wider shot of the two, as now together, arm in arm, they look out onto the horizon. This sequence is followed by a coda, set some time after Helen's death, with Jane sat with Sam on the same bench as before. She hands him a letter with her end of life wishes as "not everyone can have that serious talk". They share a joke about Helen's hair remover cream and the film ends.

Fig. 6: Stills from the end of *Dying to Know* (2011)

Whilst trying to capture aspects of individual *responsibility* towards the dying individual, the film ultimately leaves us with a rather sanitised – indeed, fantasised – vision of death and dying. From the outset, the finalities of death are made safe by the constant presence of Rod, serving to shore up Helen's – and moreover, the spectator's – ontological security. The ending projects further possibilities of companionship in an afterlife and promises a tranquil passage towards it. Aside from an evening out drinking and her weekly visit to a hospice, we learn little about Helen's everyday life. We don't even discover what she is dying of. This is curious, as the major message the film seeks to impart is precisely that public unfamiliarity with end of life fosters barriers of taboo which inhibit communication. Indeed, the title – *Dying to Know* – is reflective of this and yet the film occludes from view large parts of what is hidden, moving entirely away from realism during crucial moments. Indeed, it is perhaps telling that Helen herself turns to a film to help articulate her thoughts. Furthermore, the only impediments to Helen's "good death" are presented as contained within the family unit, ignoring entirely any wider community barriers or structural institutional and social constraints.

Mary Bradbury's study *Representations of Death* (1999) "identified three existing representations of the 'good death'": those seen as "spiritual", those which "conformed to an idealized vision of a medically controlled event" or, alternatively, those which "were seen to be rejecting what is increasingly viewed as an over-interventionist approach to dying" (p2). For Tony Walter, the contemporary "culture of individualism that values a unique life uniquely lived" has meant "the good death is now the death that we choose" (1994, p2). This may well be true, but the crucial word is "choose": what we wish, and what we project for ourselves, may actually be far from what we get. Moreover, that vision of a "good death" doesn't necessarily stem from the actualities of dying, but instead from cultural products. For example, a devastating four-year study in American hospitals reported in 1996 that 50% of terminal patients spent the last three days of their lives in "moderate to severe pain" at least half of the time (cited in Matzo and Sherman, 2009, p83). There is thus a need to recognise such realities; otherwise the "good death" simply becomes a means through which the "perceptual world of the living" pacifies anxieties by promising that "our" death can be better than "theirs".[48]

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[48] Pertinent to constructions of the "good death" are the stereotypes conjured to describe – and devalue – the dying individual. Paul Sinclair (2007, pp131–132)[48] usefully summarises these as: "*the holy innocent*", seen as "special", "blessed", "wise" and also, particularly with the elderly, often infantalised as a "once-again child"; "*the sick person*" whose fate is managed by medical professionals and institutions; "*the object of pity*", whom is held to be blameless for a condition which, nevertheless, others may resent having to support; and finally "*the dying/already dead/as*

The institutional approach to the problem of death – enveloping the dying individual in a framework of clinical care – historically resulted in the absenting of their subjective presence. Healthcare reforms in the last few decades have typically trended towards softening the medical grip[49]. However, such reforms have generally sustained an objectifying discourse. The dying individual is still constructed as somebody to be clinically done to, it's just that the doing to can be improved. Paul Sinclair has pointed out problems inherent in this approach, namely that this does little to improve the individual's wholly devalued status within the social and cultural sphere, sustaining the label of "dying" as being the person's most significant human characteristic (2007). The true reformation of end of life care has to step out of such a framework and rethink itself in a way that shifts the approach from doing *to* towards doing *for* or *with.* This refiguration, where the individual's wishes, wellbeing and experience is primary, requires not just the simple de-institutionalisation of care, but a radical challenge to society's current relationship to illness, dying and death.

My focus in what follows is anchored around end of life care reforms in the UK. This stems in particular from my own involvement in the aforementioned exhibition, which I evaluated for NHS West Midlands. However, the issues raised are, I would argue, applicable across Western states where death has become taboo and dying unfamiliar, in spite of the differing health care systems. That is, my

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good as dead", which echoes Kellehar's (2007) "social death", wherein the community regards the dying individual as having outlived their purpose.

[49] The most significant development was probably the emergence and philosophy of the hospice movement in the 1960s (see Saunders, 2005). More recent examples would be the British hospital based innovation, the Liverpool Care Pathway for the Dying Patient.

concerns are broad and unbounded by the specificities of national boundaries.[50] The structural problems that concern me are consistent. The dying individual's existence is typically "managed" through institutionalisation, isolation and stigmatisation. A lack of public familiarity with dying means that others often project wishes of a "good death" onto the dying individual. They become surprised, confused and angered when realities are not quite so simple. Equally, fear of the unknown and taboos around dying often inhibits communication. Changes to the *status quo* must work from within the community towards ensuring that the dying individual is not simply returned to "the perceptual world of the living" but welcomed there as a fellow traveler. I will be arguing that to achieve this end of life care reforms should encourage *solidarity* with the dying individual, not least as a means to identify and unsettle the structures of otherness which presently constructs them as flawed citizens. As such, I argue that the rhetoric of "*compassion*" common to many reform efforts can be problematic as it fails to challenge the complicity of citizens in accepting the *status quo*.

Firstly, though, it is necessary to outline what is meant by "end of life care", a term which, like "dying", lacks fixed meaning, especially depending on which organization, or individual, is invoking it. The term is also often conflated with "palliative care", however that has historically been more of an umbrella term inferring care orientated towards *relief* of symptoms, rather than *treatment* of symptoms, and lacking the temporality inherent to "end of life". In 2006, the British National Palliative Care Council proposed the following working definition of end of life care:

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[50] For an interesting discussion of "global perspectives" on end of life care see Singer and Bowman (2002).
Also, Nash, Sano and Vohra for a study comparing end of life care across the world (2010).

> [End of life care] helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (Department of Health, 2008, p47)

We see here, then, recognition that dying isn't merely a biological process, but a social and existential one.[51] However, perhaps reflecting the definitional genesis, the dying individual remains framed through a medicalised lens as a "patient". Equally, the "family" takes on a much wider role, and suggests the need for *their* wellbeing to be supported alongside that of the "patient". Of course, "family" is itself rather problematic, potentially excluding people central to the dying individual's life. However, despite this definition's broad framing, it is but one of many "official" definitions, with yet more interpretations stemming from colloquial understandings by patients and their families. Stephen O'Connor considers the definitional problem through a study of the available literature, concluding that:

> the nature, scope and duration of end-of-life care, together with the factors which trigger its initiation are far from understood, and still less agreed by health care professionals, whilst the 'general public' are scarcely aware that it exists as a separate entity from the broader remit of palliative (and to a lesser extent, supportive) care provision. (2008, p29)

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[51] This also reflects the World Health Organization (WHO) definition of palliative care as cited on their website: http://www.who.int/cancer/palliative/definition/en/ [Accessed September 28th, 2012]

He continues with this troubling observation: “very little consideration has been given to listening to the views of those in need or receipt of such services” (pp29-30). O’Connor’s core concern is that reforms may attempt to simply restructure existing services, with authorities perceiving problems through the framework they currently provide, rather than growing end of life care from a bottom-up approach which is built upon the needs and wishes of the dying individual. There is thus a risk that, however well intentioned, in seeking to renaturalise death end of life care reforms may institute a new set of normative assumptions about the dying individual that continue to construct them as flawed citizens, separate and other from the living.

Interestingly, O’Conner finds a certain universalism to the thoughts and fears of the dying individual, noting that “it is clear from the literature that patients’ end-of-life concerns remain the same across different client groups, racial, social and ethnic divides, as well as international borders and historical epochs” (p30). In a later chapter, I will argue that the commonality of dying – we are all, fundamentally, dying individuals – provides an ethical perch of universal experience which permits a wide-reaching unraveling of objectifying discourse. From this perch, there exists much scope for reciprocal exchange and progressive pluralistic social development. However, to achieve that, there needs to be a willingness by citizens to accept their complicity in submitting to existing structures of otherness. Visual culture can be a means of achieving this, but also risks being a vehicle through which the *status quo* is sustained.

In July 2008, the Department of Health launched the National End of Life Care Strategy, intended to significantly reform death and dying in the UK. Leading health think-tank The King's Fund described its publication as having "radically raised the profile of end-of-life care in England" (Addicott and Ross, 2010, p*vi*).[52] It was based on the understanding that the present treatment of dying inhibits, or indeed runs counter to, people's wishes for themselves and their loved ones. Whilst it is perhaps unfair to judge a strategy by its cover, the strategy document itself and all three subsequent annual reports have the exact same image and quote on the front (Department of Health, 2008, 2009, 2010, 2011). The four separate but blended pictures are of elderly citizens, one man and three women, all white, each looking to one side, and none catching the other's (or the spectator's) gaze [fig. 7]. Underneath is a quote by Dame Cicely Saunders, described as "founder of the modern hospice movement": "How people die remains in the memory of those who live on." Whilst not underestimating the time constraints of producing original cover designs, the fact that this combination of imagery and quote has lasted over four reports suggests that on some level at least, it strikes a chord with those driving the strategy.

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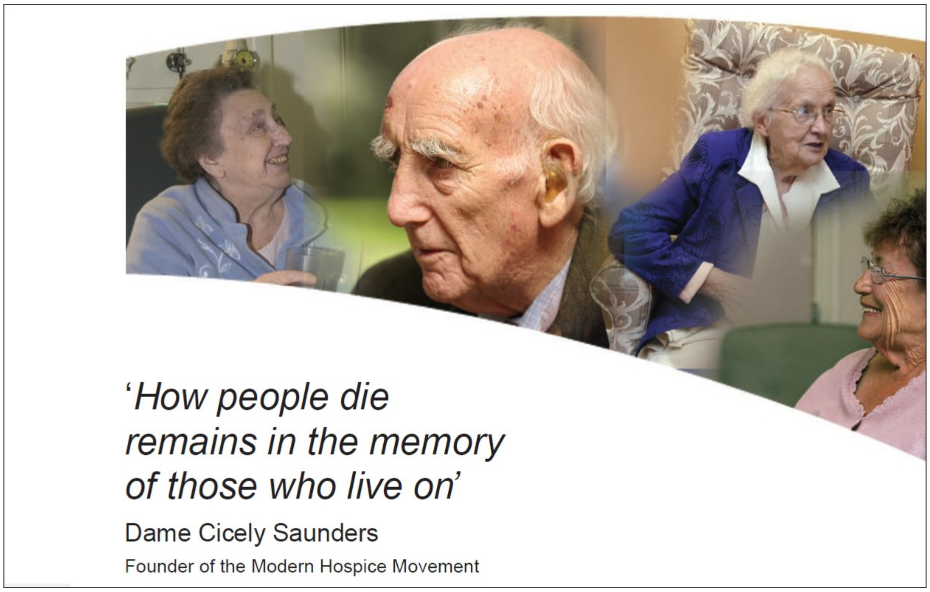
[52] The strategy was backed for the first two years by £286 million in public funds, to be distributed by ten regional Strategic Health Authorities (SHAs) and the Primary Care Trusts (PCTs) under them. The SHAs had a large amount of autonomy in how they chose to disperse the funds, enabling the development of region specific strategies. SHAs typically spent their funds on training and public education schemes, whilst PCTs provided fiscal support for institutional restructuring and refurbishment. Some funds were also specifically earmarked to support hospices. However, a general election in May 2010 brought about a change of government. With it, came plans for a major restructuring of the NHS, including the abolition of SHAs and PCTs (Department of Health, 2010b). Whilst the third annual report of the End of Life Care Strategy seeks to strike an optimistic note, it is clearly currently a time of real turbulence (Department of Health, 2011).



'How people die remains in the memory of those who live on'

Dame Cicely Saunders

Founder of the Modern Hospice Movement

Fig 7: Cover of Department of Health (2008) National End of Life Care Strategy

More than anything, the cover places a curious responsibility on the dying to die well, whilst also suggesting that the suffering "of those who live on" is of most concern. The choice of images is also strange. They offer an almost nostalgic air of elderly relatives and familial *bonhomie*. However, the framing of these citizens cuts them off from those they are interacting with. The context suggests that these are four dying individuals – and perhaps they are – but the pictorial cheer and home or outdoor locales offers little to signify this. Or, put another way, there is a great gulf between the encounter with these four citizens and that with Barb, Gary and David, encountered earlier (all of whom were also substantially younger). Combined with the quote, the cover seems to be suggesting that *this* is what "those who live on" would like dying to look like: cheery, engaged and with a rather healthy glow.

The strategy document introduces the notion of the "good death" in its executive summary. Whilst noting that individuals may differ in "what would, for them, constitute a 'good death'" it still continues to outline what "for many this would involve":

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings; and
- Being in the company of close family and/or friends (Department of Health, 2008, p9)

These are broadly achievable; however the second poses obvious problems. Adequate relief to stop the sensation of pain entirely will also often render an individual ostensibly comatose, and indeed the administering of such can precipitate and hasten death. However, what I wish to highlight is how the “good death” becomes a framing, a set of conditions which don’t actually demand structural changes, but are achievable within existing parameters. It is possible to achieve the “good death”, as defined, without truly challenging the “perceptual world of the living”. Or rather, it permits the *accommodation* of the dying individual within the perceptual world of the living, without substantially unsettling the structures of otherness which currently constitute the *status quo*.

Interestingly, the document only mentions the idea of the “good death” one other time, some sixty pages later when discussing “care after death”. Here, it notes (describing the role of professionals): “the support and care provided to carers and relatives will help them cope with their loss and is essential to achieving a ‘good death’”. Shortly after it is noted that, “a key element of a ‘good death’ is the timely verification and certification of death”. Here, then, it seems that the “good death” being formulated is as much a product of the perspective of onlookers as it is about the actual experience of the dying individual. By 2010 (with a new Government) the “good death” was a central part of NHS strategising. A white paper setting out major reforms to the entire NHS contained one passage about end of life care, saying “we will move towards a national choice offer (*sic*) to support people’s preferences about how to have a good death” (Department of Health, 2010b, p17).

A 2011 report by the Cicely Saunders foundation finds that the End of Life Care Strategy’s aims are “guided by the idea that a ‘good death’ is about being respected, dying with dignity and as comfortable as possible, no matter who one is, where one lives and irrespective of care setting” (Gomes, Calanzani and Higginson, 2011, p6). Just below this sentence is a picture which makes for an interesting and rather problematic illustration [fig. 8].

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Fig. 8: Illustration in Cicely Saunders Foundation report[53]

Perhaps this picture was intended to give spectators a positive projection of what a “good death” could look like, but in many respects it represents reforms that fail to significantly unsettle current structures of otherness. The dying individual is barely

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[53] Gomes, Calanzani and Higginson (2011, p6).

perceptible, occluded from view by the table and plant. The person's just-visible face is all but a blur, almost blending with the yellow of the pillow. Far more clear and obvious is the large empty chair in the foreground at the end of the bed, symbolizing the possibility of companionship which is presented here as nevertheless non-existent. Dominating the image is the light-green tree which appears to rise from the centre of the medicalised bed, framing the dying as "natural", whilst also alluding to a symbolic "tree of life". This is also the only picture in the report where a dying individual is present. Others are of a river flowing amidst autumnal trees (p9), a series of stepping stones in a lake (p17) and sun flowing through the bright green leaves of a tree (p20). We will shortly see the extent to which nature serves as a "people–free" metaphor for death and dying, when considering the photographs taken for the NHS exhibition.

Whilst the notion of the "good death" may inform the projected goals of reforms, a more precise target is used to measure the success of the End of Life Care Strategy: the location where dying takes place. This is, I suggest, connected to a cost-cutting imperative. The strategy document notes that recent surveys, focus groups and interviews have consistently found that "most […] people would prefer not to die in a hospital" (Department of Health, 2008, p9). A similar figure was found in a 2010 YouGov survey, where 66% of citizens said they wanted to die at home, with only 7% wanting to die in hospital (Leadbeater and Garber, 2010, p13). However, in 2008, of the roughly half a million deaths annually, "[m]ost deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere". By 2030, if 2008 trends continued, the number of deaths in institutions was projected to increase by over 20%, with home deaths falling to only 9.6%. By contrast, in around 1900, "about 85% of people died in their own homes, with workhouses accounting for most other deaths" (Department of Health, 2008, p9).[54]

The strategy is having some success, at least by its chosen measurement (or "vital sign"). Whilst for the first few years, success was being measured on how many people were dying in their homes, in 2011 this was expanded to include care homes, meaning the strategy's chief target was to increase the number of people dying in their "usual place of residence" (Department of Health, 2011, p8). The most recent figures, from 2010, demonstrate a decrease in hospital deaths (from 58% to 53%) and an increase in home (up nearly 3% to 20.8%) and hospice deaths (from 4% to 5.3%). The number of deaths in care homes also rose, from 17% to 18.5%, meaning that "39.3% of people die in their usual place of residence" (p18). There are, though, reasons to perhaps be a little cynical about why place of death was the target settled on, particularly given the recommendations of an extensive report prepared for the National Audit Office in 2008 entitled, "The potential cost savings of greater use of home and hospice based end of life care in England" (Hatziandreu, Archontakis and Daly, 2008). Annual spending on end of life care was found to be many billions. To give one example, the report estimated that "the cost of providing care in the last year of life to the nearly 127,000 patients who died from cancer is approximately £1.8 billion, corresponding to £14,236 per patient" (p1). It also cites a 2004 study which suggested that £2 could be saved "for each £1 spent on home and support care" (p7). Similarly, a 2011 study, commissioned by

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[54] In *The Living End*, Guy Brown (2008) notes various contributing factors to such figures. Particularly concerning is the increasing numbers of elderly people with chronic physical and mental conditions requiring direct care. This can often only be provided institutionally because of their isolation from networks of family or communal support. He also notes the stark difference between the rise in "life expectancy" as opposed to "healthy life expectancy", the age to which one can expect to sustain good to fair health. In the UK, between 1991 and 2001, life expectancy rose by 2.2 years, but healthy life expectancy only rose by 0.6. Citizens, that is, are living longer and dying longer. Gomes and Higginson's (2008) study projects that "the percentage of deaths among those aged 85 [or over] are expected to rise from 32% in 2003 to 44% in 2030" (p33).

the Department of Health, argued that by 2021, £180 million per year could be saved through "optimised provision of services outside the hospital setting" which could reduce the number of hospital deaths by up to 60,000 annually (Hughes-Hallett et al, 2011, p9).[55] This is simply to suggest, therefore, that an economic imperative could be at the heart of the End of Life Care Strategy, particularly given that it was implemented amidst the fiscal chaos of an international recession, which has seen large cuts in public spending.

When developing the strategy, the "widespread reluctance to discuss issues of death, dying and bereavement" was found to be a central reason "why people were often not able to be cared for and to die where and how they would have preferred" (Department of Health, 2009, p19). Such a curtailment of open communication engenders the stigmatisation of the dying individual and helps sustain the *status quo* of institutionalisation, medicalisation and isolation. Consequently, a national coalition organisation, *Dying Matters,* was created "to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm".[56] Concurrently, regional Strategic Health Authorities (SHAs) were given a certain freedom to develop their own programmes to tackle taboos around death and dying. I turn now to the work of West Midlands SHA and the exhibition mentioned above.

"Saying the Unsayable: Opening a dialogue about living, dying and death", was a three-day exhibition held in the centre of Birmingham on July 2nd-4th 2009. It offers

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[55] In America, according to a report by CBS, in 2008 Medicare health insurance "paid $55 billion just for doctor and hospital bills during the last two months of patients lives". It adds, "it has been estimated that 20 to 30 percent of these medical expenses may have had no meaningful impact" (CBS News, 2010).

[56] *Dying Matters* "About us" website page: http://www.dyingmatters.org/overview/about-us [Accessed September 28th, 2012] *Dying Matters* produced the film *Dying to Know* (2012) discussed above.

a useful lens through which to consider current efforts at end of life care reform, but also to develop wider questions regarding visual culture, dying, citizenship and spectatorship that will be pursued in subsequent chapters. The exhibition was held as part of a regional strategy (Smith, 2008) which was then in development by NHS West Midlands SHA within the wider national strategy. Drawing on Allan Kellehear’s *Compassionate Cities* (2005), the regional strategy sought to develop civic awareness and engagement with the intent of improving the quality of a person's perceptions and experiences of death, dying and loss. Adopting the idea of “resilience” and “resilient communities” – the idea that health services should encourage, build and support individual and community traits which can be called upon and drawn from at times of adversity – the regional strategy was guided by the need to “take a whole community approach”, “be inclusive of all parties within a community” and "be of a collaborative, participatory and partnership character” (Kellehear and Young, 2007, p226). Accordingly, it aimed to address the social and cultural obstacles which currently foreclose broad communal support for the dying individual.

To achieve the objective of “whole community” inclusion, the exhibition itself primarily displayed locally produced photographs, taken by a variety of groups (including schools, a cricket club and a carers centre).[57] Across the twelve community groups, ninety-six participants were given basic photographic training and provided with a camera for two weeks. They were asked to take pictures following a series of prompts specifying: “loss”, “living well”, “care”, “compassion”, “death or dying”, “what brings you to life” and “what deadens you”.

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[57] The community groups were: K–Kats Youth Club, Out Central LGBT Youth Project, Birmingham's Older People's Reference Groups, The British Oak Pub, King Edward's School, Moseley ARC, Moseley School, Kings Heath Cricket and Sports Club, Birmingham Carers Centre, Falcon Lodge Youth Centre and St John Wall Catholic Secondary School.

Over eight thousand photographs were taken, around a hundred of which were selected for exhibition by the organisers. The photographs were divided into themes, which were:

- The West Midlands connections: decay, regeneration and renewal
- Juxtaposition and the fine lines: being alive, hope and death
- Compassion, attachment, love and connections
- Remembrance and continuity
- Living life well, life as a journey
- Metaphors and symbols

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Fig. 9: Visitors at the exhibition *Saying the Unsayable*[58]

At the exhibition, the themes were presented on coloured cube structures, each of which contained a selection of photographs [fig. 9]. Every photographer was

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[58] This and other photographs from the exhibition are taken from the *Wellbeing in Dying* website (http://www.wellbeingindying.org.uk/), or from the wider selection of pictures taken to which I had access.

invited to provide a caption to their image, although it was noted in the guidebook that each photograph "may evoke quite a different meaning, thoughts and feelings for you the viewer" (NHS West Midlands, 2009, p13). The exhibition also included a locally produced documentary and ten photo-essays, where participants provided short aural accounts which were played over a series of their own photographs. There was also a computer terminal where visitors could view even more images. The centre of the exhibition space was a kitchen table where a theatre company called ONCE held regular interactive performances to encourage conversations about death by visitors.[59]

The "dialogue" the exhibition sought to open was identified by the organisers as a necessary first step towards overcoming basic interpersonal barriers of taboo, unfamiliarity and uncertainty surrounding death. And in this it was successful. Put simply, it got people talking and often quite openly: a positive response evident from written feedback made in the visitor comment book and the observations of organisers. I evaluated the project for internal use by the organisers.[60] To quote from my conclusion:

> Visitors responded strongly to the fact that the pictures were the product of people just like them. The subject was made familiar and recognisable with images that treated the topic both literally and symbolically, personal and universal. The photographs ranged from loss to life and in so doing made plain how the two are not opposites. Equally, the weight given to

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[59] Exhibition materials and commentary by the organisers can be accessed at the *Saying the Unsayable* website: http://www.wellbeingindying.org.uk [Accessed September 26th, 2012]. See also Smith (2010) for a report by the project lead.

[60] My evaluation used evaluation forms completed by the participants who took the photographs, the exhibition comments book, formal and informal reports written by project organisers and discussion with Pauline Smith, the project lead. I also had access to the complete set of photographs (8,000+) taken by participants (Horne, 2009).

> community decline, from boarded up pubs to derelict buildings, extended the subject spatially and made it a full part of the lived everyday. There was a recognisable regional quality to many of the photographs, which acknowledged the importance of the local environment as a place where living, dying and death are played out and given meaning. (Horne, 2009)

The organisers themselves were pleased with the results, noting that the use of visual imagery "provided a very useful start and method and route into the territory of articulating and sharing aspects of living, dying and death in very accessible and acceptable ways" (Smith, 2010). The photographer who oversaw the project commented that the images were "not only meaningful to each photographer, but also relevant to us all" (Marsh, 2009). Following its success, the selected photographs were subsequently trialed as a resource pack for schools and other organisations.

Writing in the guidebook, project lead Pauline Smith described the decision to use visual culture because: "We increasingly need to find a language, a form of words and shared ways of knowing for how to bring up the subject of dying and death and dialogue with others" (NHS West Midlands, 2009, p6).[61] The work of Sandra Bertman (1991), who advocates the use of imagery as means of death education, was a strong influence on Smith.[62] Bertman argues that visual culture "enable[s] us to probe the human condition in language that is symbolic rather than

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[61] For a broad range of examples of where art and culture in general has been used in palliative care, both as a therapeutic tool and in terms of awareness, see Hartley and Payne's (2008). See also Richards (2011) on the organisation *Rosetta Life*, a collective of artists, who work in hospices to tell the stories of patients using a variety of mediums.

[62] Early inspiration was also provided by an exhibition of photographs taken by Walter Schels entitled *Life Before Death*. Schels photographed twenty-four terminally ill people before and after their death. For a selection of these photographs see the Wellcome Collection website: http://www.wellcomecollection.org/whats-on/exhibitions/life-before-death.aspx [Accessed September 28th, 2012]

literal, suggestive rather than didactic" (p167). She has seen how "images can elicit responses and attitudes toward death heretofore unspoken or acknowledged even to ourselves" and has found that her work demonstrates how "death, like birth, is an archetypically communal experience with universally shared emotions, fears, hopes, and pains – an event that ironically has *not* changed despite advanced technology and sophisticated medical care" (p6, p167; emphasis in original).

I share Bertman's enthusiasm for visual culture, however, as will become apparent, I think there are some essential reservations to be made. Specifically, visual culture – and in more forceful form, the Spectacle – currently contributes to the stigmatisation of the dying individual and the public unfamiliarity with the actualities of death. Indeed, as I have argued, it currently works to preserve the ontological security of the spectator and preserve the *status quo* by constructing the dying individual as different from the "living". Recognition of this needs thus to be factored into any approaches which depend upon visual culture.

The exhibition guidebook emphasised the "unfamiliarity with the features of dying in the 21st century", noting that "it is now not unusual to reach the age of 50 or so before we are witness to such an experience or even to be in the presence of a dead body" (NHS West Midlands, 2009, p6). The dying individual was, however, to a large extent, the structuring absence of the photographs taken. The images I will shortly discuss are the only ones from the more than eight thousand photographs, which signify the dying individual. Curiously, the absence of dying in the community produced photographs was augmented in the exhibition by a selection of outside images. These were taken from news agencies, and showed foreign – and violent – deaths [fig. 10]. For many reasons, I find these photographs an odd and troubling substitute. However, they also make stark the extent to which actual death has become estranged in the West: remote, foreign, other, and something that happens to *them* not “us”. These images also foreground the site where we mostly encounter dying in everyday life – mainstream visual culture – and thus brought the Spectacle into the heart of the exhibition space.

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Fig. 10: Two pictures exhibited under the theme “Juxtaposition and the fine lines” at the exhibition *Saying the Unsayable*

Every Day a Little Death, the documentary produced for the exhibition, replicates this absence of the dying individual.[63] It opens with a sequence shot from the point of view of a dead body, exiting a hospital, being taken to an undertakers and eventually entering a crematorium furnace. The film features a series of interviews with professionals and academics, but doesn’t include anybody who is dying. Even shots taken in a nursing home carefully keep the residents out of focus, or, through tight framing, show them only as a fragment of their bodily whole.

The broad absence of the dying individual from the exhibition raises the concern that that the exhibition unintentionally (indeed, unconsciously) perpetuated the *status quo*. If the subjective presence of the dying individual is typically mediated and occluded from socio-cultural view, such an absence at the heart of reforms

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[63] It can be viewed on the *Wellbeing in Dying* site: http://www.wellbeingindying.org.uk/reflections-on-dying-and-death.asp [Accessed September 29th, 2012]

aimed at rectifying this is troubling. The broader implications of this are raised by Christian Metz, in terms which resonate with the current discussion:

> The character who is off–frame in a photograph, however, will never come into the frame, will never be heard – again a death, another form of death. [...] It marks the place of an irreversible absence, a place from which the look has been averted forever. (1985, p87)[64]

In the single image, the off-frame is potent, but unknowable. However, the several thousand photographs taken for the exhibition, and the context through which they were made and displayed, provide a means of seeing it literally and psychologically. Indeed, the community nature of the photographs' production, the amateur status of the participants and the resulting "snapshot" or "personal" aesthetics of many of the pictures, helps us to see more clearly the socio-cultural frames which manage death. Photographs, such as those taken for the exhibition, lend themselves well to an analysis of the frame. As Susan Sontag observed: "[the photograph] is always the image that someone chose; to photograph is to frame, and to frame is to exclude" (2003, p41).

As I have argued, dying has become falsely understood as the *other* of living. I suggest that this stems from a belief, or perhaps a wish, that messiness and uncertainties of death can be safely contained within a framework, whether in the literal frame of visual culture, or wider frames at play socially, not least the notion of the "good death". Consequently, the encounter with the dying individual is

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[64] By "another form of death", Metz, recalling similar comments by Roland Barthes in *Camera Lucinda* (1981/2000), is referring to the "immobility and silence" which figure both death and the photographic image. Equally, Metz alludes to the ability of photography, through old pictures, to retain the dead in the present, as well as its act of capturing and embalming the living in a frozen moment that can never be relived or recaptured.

always already foreclosed. As we shall see, the photographs replicated this dynamic, which I suggest is partly a consequence of the emphasis on creating compassion towards the dying individual from the perspective of the spectator. Instead, I advocate “solidarity” over “compassion”, achieved through a rethinking of how the dying individual’s citizenship is constructed and communicated. As such, it behooves end of life care reforms to acknowledge and unsettle the structures of otherness present in Western visual culture which seek to frame the dying individual as separate from the “living”.

Michele Aaron (2009), in an essay written for the exhibition guidebook, analysed a selection of two thousand photographs. Aaron notes that the “vast majority [...] [of the photographs] had little to do with the topic of mortality”; those that did generally approached the subject “figuratively”, finding “metaphors for ‘our' death through displacement”, particularly in images of “disuse and dilapidation” within the community but also in winter scenes and natural decay. Photographs that directly spoke of death and dying “did so with varying degrees of explicitness”. Most common were shots of graveyards, alongside “occasional nods to death's infrastructure or industry”. However these latter shots of medical and funerary institutions “tended to be highly objective – insulated, mostly, against emotion, often people-free” standing in contrast to the many, mainly joyous, photographs taken by the participants of their families and friends.

This becomes even more apparent when considering the complete set of images. Here, there are many, many photographs of families and friends simply hanging out or having fun. Looking through them, one gets the sense of sifting through a private family or Facebook album. Indeed, the many, multiple attempts to get a group photo just right indicate the ease by which people are generally caught on camera. The vitality and interpersonal connectedness displayed in the pictures of people, contrasts with the objects and landscapes (and “often people-free” infrastructure) selected to represent death and dying. This stark contrast suggests a synthesis, whereby the dying individual re-enters the social frame surrounded by the warmth of companionship. However, such a possible synthesis sounds a very real alarm: the sustaining of a “highly objective” gaze which structures the dying individual as separate from the “living”.

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Fig. 11: Photograph taken for the NHS West Midlands project, but not exhibited

This alarm is crystallised in one image, taken at a hospital bedside, although not used in the exhibition itself [fig. 11]. Two people, sat at the end of the bed, face and greet the camera, whilst a third, the patient, can only be inferred through a visible bulge in the blanket. What makes this picture particularly resonant is that it's the only image taken at the hospital by that participant. Accentuating this particular exclusion of an individual whose absence nevertheless defines the image, is how thoroughly personal so many of the photographs are, capturing a level of private minutiae that often seems out of place for potential public display. Or rather, an axis suggests itself. At one end are the images of “living well” and “what brings you to life”, which are the most private, in that they resemble the sort of snaps every family takes of itself and its activities. At the other, those of “death”, “loss” and “dying” are the most public, in that consciousness of composition, audience and exhibition come to the fore. In making public the private, the frame imposes itself most forcefully the more the photograph speaks of death. This echoes Geoffrey Gorer’s sense of the “pornography of death” which John Tercier elucidates as, “the explicit (the private made public) representation (mediated act) of a forbidden act (the transgression of social norms) for the purpose of arousal (the eliciting of desire)” (2005, p213).

Within the perceptual world of the living, the un-sightliness of the dying situation, and the dying individual, sustains, generally, an off-frame existence. The spectator need not look away. The camera already did so. However, this begs a crucial question: for whose benefit is this? The selection of one of the photographs displayed in the exhibition, from a sequence taken at the same time, suggests that the spectator is given first consideration [fig. 12]. The series concerns an elderly woman, lying down. The woman is either pictured alone, sleeping, or joined by a young boy (perhaps her grandson). Of the two pictures with them together, one is tightly framed on their heads, with her barely awake face pressed against the child as he looks to the camera. The other, wider, encompasses their bodies as the child, forehead against cheek, looks angelically up at her. The latter was chosen for exhibition under the theme, “Compassion, attachments, love and connections”.

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Fig. 12: Photographs taken by a participant in the NHS West Midlands project

It is the most sentimental of the four images, packed with affect. As such, it is the easiest to see. It implicates the spectator least. The photograph communicates a particular message: this woman has the love of her grandchild and, through him, life goes on. However, it says little beyond this. Indeed, it tends to lend itself to consideration of the child, rather than the dying individual. Such a reading was reinforced by the caption for the image (provided by the photographer): “this photo tells me that when someone dies a new baby takes their place”.[65] Photographs which communicate at the level of affect may well provoke a moral response – here, the importance of companionship to the dying. But such a response from the spectator typically resists any deeper consideration of complicity in, say, individual and societal failures to provide the comfort of companionship to the dying. That is,

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[65] The picture and caption as displayed is available at the following website: http://www.wellbeingindying.org.uk/theme–three.htm#11 [Accessed September 27th, 2012]

complacency rather than complicity is encouraged through being moved by the companionship that this particular woman, who, at this specific moment, as captured by – and seen in – this photograph, has. The most constructed image was perhaps picked because it communicates simply and safely, reducing complexity and subjectivity by implying that everything is being said within the frame.

The other image that figures dying that was chosen for the exhibition, also displayed under the theme, “Compassion, attachments, love and connections,” offers a potent example of how a frame can efface the subjective presence and agency of the dying individual [fig. 13]. An elderly woman is in a bed, in a home environment, being looked after by another, younger, woman wearing a plastic apron. The series of images matter-of-factly reveals banalities, such as incontinence pants and restraining cot sides on the bed, and suggests the woman may be in distress. The photograph selected for the exhibition frames an act of clinical care – an injection is being given – whilst maximising the privacy of the woman: her head is hidden by her hand, as if she's turned away from the camera in shame. The spectator’s eye is guided, through the composition of the image, towards the woman's carer. The photograph, alone, seems to be offering the most palatable – for the spectator – presentation of a difficult situation; it is unfortunate that the woman has to hide her face, but at least she keeps her dignity.

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Fig. 13: Photograph exhibited at the exhibition *Saying the Unsayable*

Only this reading – a reading which appears complete, which appears to account for everything within the frame – is utterly mistaken and exposes the spectator's desire to allow the frame to inscribe meaning. In actuality, the photograph – of mother and daughter – portrays play. Whilst being given her medication, the mother was having fun by hiding from the camera. This "correct" reading of the image was supported in the exhibition by the caption provided by the daughter: "I took this of my mum. I was doing her medication. This photo shows care, friendship and support for someone in need. Also loss and change. It makes me smile as Mum was hiding as we were taking her photo and laughing and playing a game."[66] Indeed, the spectator's act of looking at the photograph potentially situates them as an active – and necessary – participant in this game. By unsettling the frame, the spectator is drawn into a private world, untethered from the dictates of public discourse.

John Berger's observation that "[t]he private photograph [...] is appreciated and read in a context which is continuous with that from which the camera removed it" (1980, p51) speaks to just how much context is lost when the private is made public.

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[66] The picture and caption as displayed is available online: http://www.wellbeingindying.org.uk/theme–three.htm#1 [Accessed September 28th, 2012]

The photograph may well demand to be looked *at*, but an awareness of context, of what is hidden, both temporally and spatially, by the frame, or, at the very least, an awareness *of* the frame, suggests itself as an essential component of looking. In both examples, awareness of the broader spatial and temporal context work towards restoring the lived existence of the dying individual. Following Ariella Azoulay (2008), we can say that this is an act of "watching".

In *The Civil Contract of Photograph*, Azoulay aims to conceptualise "a space where 'thinking of a politics freed from the form of the State' becomes possible (2008, p88; citing Agamben, 1988, p109).[67] She takes the practice and reception of photography as a model through which citizenship can be turned into an active, ongoing, engaged struggle of solidarity, challenging the legitimacy of governing structures which fail to treat citizens equally. The state makes normative categories such as "flawed citizens", marking out people who are governed and subject to its authority, but are otherwise absented from full civic consideration. However, citizenship can be reconceived in opposition to this as a contractual arrangement between and amongst all governed individuals, whereby each citizen is the guarantor of the other's rights. For Azoulay, this can be understood as "multiple voluntary associations between many individuals, which reproduce the original moment of contract without necessarily reproducing its result, that is, the constitution of a sovereign authority" (p87). The potential therefore exists to formulate "a politics founded on the equality of the governed, [where] power

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[67] Azoulay articulates the tension between citizenship as typically practiced and citizenship as intended. That is: an original contract between people who are governed is formulated. This formulation occurs to protect against individual suffering by guaranteeing rights to people. However, the protector of citizenship is typically conceived as the sovereign authority. The contract is necessary because that authority would generally tend against acting as a guarantor of rights to all. Consequently, the sovereign authority is given power to determine who is, or who is not, a citizen. Such power, then, creates the potential for structural inequality, where citizenship is not afforded to all those who are governed.

regains its meaning, not as a governmental tool, but as ‘a human ability not just to act but to act in concert’ and to negotiate, sometimes successfully, sometimes not – with sovereign power” (p88; citing Arendt, 1970).

Azoulay insists that nobody holds a monopoly over photographic meaning, however, it is all too easy for the photographed individual to become effaced: to exist as an object encountered through the framed gaze of spectator and photographer alike. Azoulay emphasises that the photographic encounter is one between spectator, photographer, photographed and camera. The camera literally produces content, but it is the interplay and exchange between the other three which produces meaning. Azoulay argues for the necessary understanding of the situational particularities of photographer and photographed. This temporal and spatial inclusion therefore requires the spectator to “stop looking *at* the photograph and instead start *watching* it” (p14; my emphasis). Spectatorship thus becomes a performative act of citizenship if and when it recognises the demands and the agency of the photographed person against current governing structures. Accordingly, the act of unsettling structures of otherness actually offers the spectator real civic agency, shedding shackles of selfishness by reorienting their gaze towards the other. The encounter between spectator and dying individual ceases being about projections of the “good death” and instead instates *responsibility* into the act of watching.[68] Crucially, this is not a responsibility of compassion towards another’s suffering, but rather, through solidarity, a responsibility that comes with recognising the structures that maintain and sustain their suffering. The following chapters, through photography and film, will trace this responsibility into the realm of the ethics of spectatorship.

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[68] Tanner (2006) discusses something similar with her notion of the “terminal gaze”. I will consider this in more detail in the following chapter.

The photographs that were chosen for exhibition bracket the spectator's encounter with the dying individual within a structure of care and compassion. They displace the spectator's gaze away from the dying women and towards the grandchild and daughter respectively. This shift works to prioritise care and compassion towards the dying individual over responsibility for ensuring their equality. Moreover, it provides the spectator with a ready solution for reform – more care, more compassion – rather than encouraging contemplation about the actual lived experience of the dying individual and the structures which render him or her as different from the "living". Susan Sontag's consideration of compassion in relation to emotions evoked by photographs is instructive here:

> Compassion is an unstable emotion. It needs to be translated into action, or it withers. The question of what to do with the feelings that have been aroused, the knowledge that has been communicated. If one feels that there is nothing "we" can do – but who is that "we"? – and nothing "they" can do either – and who are 'they' – then one starts to get bored, cynical, apathetic. (Sontag, 2003, p101)

Allan Kellehear's *Compassionate Cities* (2005) was a central influence on the strategy developed by NHS West Midlands, of which the exhibition was a part. In the book, Kellehear advocates a restructuring of organisational care, the development of new services and the forging of strong community networks of support. Compassion, for Kellehear, is "the human response, the tender response aroused by the distress and suffering of others" and should be considered an "ethical imperative for health" (2005, p43, p44). More generally, "compassion" is routinely advocated as a necessary component of end of life care. For example, a 2011 conference described palliative and end of life care as “the science of compassion”[69]. Similarly, a World Health Organisation training document advises health workers to be “present with compassion” in their approach towards the dying (2003, p46).[70] The term also, of course, carries strong religious connotations.

Compassionate Cities is complemented by work on “health-promoting palliative care“, which establishes a set of principles that insist upon “the essentially *social* character of health and illness”. As such, Kellehear argues that “health care should be participatory, not something we *do to others* but a style of health care that we *do with others*” (2005, p25; emphasis in original). Kellehear sees as essential the recognition that historically “care of the dying [...] has been a normal and routine matter for families and communities” and we must, once again, recognise “dying, death, loss and care as normal and usual experiences for which communities can and should take some responsibility” (p13, p34). He also advocates the need for developing “resilience”, traits and resources which can be called upon and drawn from at times of adversity (Kellehear and Young, 2007).

Paul Sinclair (2007) offers a useful critique of Kellehear’s approach, cautioning that his emphasis on the universality of dying and loss fosters an “idealised understanding of death” and fails to prioritise and centrally address the question of social devaluation. Sinclair’s concern is that “compassion”, for Kellehear, is orientated more towards the benevolent relief of suffering, rather than an

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[69] ‘The Science of Compassion: Future Directions in End-of-Life and Palliative Care’, August 10–12, 2011. More details online: http://www.ninr.nih.gov/ResearchAndFunding/scienceofcompassion.htm [Accessed September 27th, 2012]
World Health Organisation (2003) ‘Palliative Care: Symptom management and end–of–life care – Interim guidelines for first–level faculty health workers’. World Health Organisation. Online: http://www.who.int/3by5/publications/documents/en/IMAI_Palliative.pdf

[70] See also, for example, organisations concerned with care for the dying like *Compassion and Choices, Compassion and Support,* and *Compassion in Dying.*

introspective interrogation of one's responsibility for perpetuating that suffering. He is not suggesting that Kellehear’s model is consciously devaluing, but rather seeking to expose the limitations inherent in its approach. Sinclair suggests “solidarity” rather than “compassion”, in an attempt to reorientate the “quasi-religious” nature of empathetic caregiving towards something closer to a struggle for equality (2007, pp96-109; pp193-196). He notes, for example, that whilst it may be a friendly, compassionate and much appreciated gesture for local community members to visit dying individuals in hospices, this does little to structurally challenge their social status. The tension Sinclair outlines, between care of the other and responsibility for the other, makes the question of responsibility central to social reform. It cautions against a gaze that, however altruistic, however benevolent, is conditioned to constitute the other – the dying individual – within a particular, ultimately desubjectifying, discourse.

The re-entry of the dying individual to the “perceptual world of the living” is therefore not simply a question of re-visibility. Rather, it demands the unsettling of the structures of otherness which instigated and maintained his or her institutionalised exclusion. Within this lies the specific unraveling of discursive attempts to enforce a separation between the “living” and the “dying”. Dying has become a private affair. Consequently, its public appearance frames the dying individual in a manner that denies their subjective presence. Such objectification is naturalised by the arbitrary social and cultural structures that produces it. The gap, therefore, between private and public is the gap between individual and structure. The “social death” of the dying individual is thus a product of the structure.

End of life care reforms are rightly identifying the social and cultural barriers of taboo as key sites restricting dialogue and inhibiting societal change. Through foregrounding the role visual culture can play in achieving this, NHS West Midlands opened up a vital, publicly accessible, arena. However, given that the visual, as argued, currently contributes to the present devaluation of the dying individual, reforms utilising visual material should be careful not to replicate this exclusion and objectification. As seen, there is a danger that prioritising imagery engendering "compassion" towards the dying individual risks perpetuating the *status quo.* Reforms must be willing to challenge the complicity of citizens in wishing to continue socio-cultural structures that consistently fail to grant the dying individual equal status in "the perceptual world of the living". Accordingly, rather than *compassion* towards the dying individual, *solidarity* with the dying individual should be sought. Solidarity involves the recognition of the dying individual's present status as a "flawed citizen" and a refusal to allow that to continue. Solidarity can be fostered through imagery which forces the spectator to ask questions about how – and why – the dying individual is currently isolated, institutionalised and stigmatised. As such, it may therefore be necessary to challenge and unsettle spectators, by way of unsettling structures of otherness. The following chapter will explore this further.

End of life care reforms should ensure that the dying individual is accorded the same civic status as all whom the reforms address. Given that this is presently not the case, any imagery utilised should be considered for its ability to challenge the complicity of spectators in submitting to the *status quo*. Equally, the spectator's wish to be freed from anxieties over mortality should be acknowledged for the harm it can inflict. Reforms have the potential to unsettle the perceived naturalness of artificial barriers by encouraging spectators to recognise and question the structures which permit the dying individual to be regarded as different – as other – from the living. Indeed, they should seek to reveal the current structure *as it is*, rather than *as it should be*. Welcoming the dying individual back within the "perceptual world of the living" necessitates identifying and unsettling all frames which seek to contain the encounter and keep the private from upsetting the public. Through seeking solidarity with the dying individual, a future can perhaps be envisaged where all citizens are equal throughout the course of their being.

The spectator's encounters with the dying individual in end of life care reforms have been partial and problematic. However, the "Saying the Unsayable" exhibition demonstrated that visual culture can provide a crucial first step towards dialogue, understanding and familiarity. In the following chapter, I will look to three different photographic projects – *Gramp*, *The Dad Project* and *Grace Before Dying* – which offer intimate encounters with the dying individual. Through readings of the images, we will not only experience sustained encounters with the dying individual, we will start to pose specific questions of ethics, spectatorship and responsibility, by way of thinking through the barriers to solidarity and the unsettling of structures of otherness.

CHAPTER THREE

FOSTERING SOLIDARITY:

PHOTOGRAPHING THE DYING INDIVIDUAL IN PUBLIC

> Death and photography seem to have a basic relationship; but it is illusionary, for the camera does not depict death, it only shows how someone else saw it.
>
> - Judith Goldman, *Village Voice,* 1976[71]

> What a critically ill person needs above all is to be understood. Dying is a misunderstanding you have to get straightened out before you go. And you can't be understood, your situation can't be appreciated, until your family and friends, staring at you with an embarrassed love, know, with an intimate, absolute knowledge, what your illness is like.
>
> - Anatole Broyard (1992, p67)

Susan Sontag, in the final article she published before she died, argued: "To live is to be photographed, to have a record of one's life, and therefore to go on with one's life oblivious or claiming to be oblivious, to the camera's nonstop attentions" (Sontag, 2004). Sontag is speaking to the contemporary inescapability of the camera's gaze and the need to accommodate that within one's existence. However, as we have seen – and as the dying individual experiences – there comes a point in life where the camera typically retreats. Not so for Sontag. In 2006, her partner, photographer Annie Leibovitz, published a volume of her work which included pictures she had taken of Sontag's dying and death. The images also featured in a subsequent solo exhibition. Leibovitz received much criticism for this. The

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[71] Quoted in Ruby (1995, p15).

photographs would be described as “voyeuristic” and even “necro-porn” (Thompson, 2007; Shaw, 2006).

Liebovitz discussed the pictures in an interview with *Newsweek*, noting that, “People have said it’s important to publish them because so much is masked from us about what the end really is”. She continues with the troubling observation that if Sontag “were alive, she would not want them published”. Liebovitz concludes that, regardless, she has “been through everything mentally and emotionally, and [is] very comfortable with them” (*Newsweek*, 2006). Sontag’s son David Rieff, however, claimed that his mother had been “humiliated posthumously” through “carnival images of celebrity death” (2008, p150). Rieff wrote these words in a book documenting, often in intimate detail, his mother’s dying. Accordingly, his comments appear perhaps a little contradictory and speak to the particular potency of the photographic image. As DeShazer (2009) observes, in a discussion of Liebovitz’s photographs and Rieff’s memoir, whilst “graphic representations of the dying strike some viewers as ethically suspect, especially when the subjects have not granted explicit permission, written texts [...] generally receive a positive cultural reception” (2009, p224).[72] Left hanging is the question of why photographic representations of dying throw up such immediate and troubling questions of ethics, voyeurism and exploitation.

The “perceptual world of the living” can be said to manage and regulate the representability of the dying individual in public. As I have argued above, the broad social and cultural exclusion of the dying individual has led to a widespread public unfamiliarity with dying, lending an air of shock to such imagery. This is compounded by the often unreal representation of the dying individual in

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[72] DeShazer ultimately finds that, for her, “both narratives […] evoke transformational mode of spectatorship characterized not by voyeurism but by reciprocal witness” (2009, p232).

mainstream entertainment and their selective framing in other visual forms. As a consequence of this, when encountered, the dying individual can be perceived as a threat to a spectator's ontological security and a challenge to their fantasies of immortality – fantasies grounded in Western individualism. Also, the belief that dying is a private affair and thus should be kept out of the "perceptual world of the living" lends an air of transgression on the occasions when the dying individual is encountered there.

As we saw in the previous chapters, the dying individual is typically kept outside the representational frame, occluded from public view. When they are visible within the "perceptual world of the living", structures of otherness ensure that any encounter with them, whether by spectator or citizen, is always already foreclosed. As Gibson (2007) argues, contemporary "technologically mediated culture" in many respects widens the "gap between 'real death' and its imagined or simulated forms" (p423). We can consider this further through what Judith Butler terms "representability" (2010, p73). For Butler, "we cannot understand the field of representability simply by examining its explicit contents, since it is constituted fundamentally by what is left out, maintained outside the frame within which representations appear" (*ibid.*). Butler argues that the frame's "jettisoning and presenting" functions invisibly, producing a spectator "who assumes him or herself to be in an immediate (and incontestable) visual relation to reality" (*ibid.*). This chapter is concerned with photographs that rupture the field of representability and help reveal the mechanisms of mediation. Specifically, I will consider images that seek to straddle – or at least, negotiate – the privacy of dying (and the private life of the dying individual) with a wish for it to be publicly seen. Following Azoulay

(2008), we will see how these pictures permit an act of *watching*, fostering a gaze of solidarity between spectator and dying individual.

In an article contesting the theory that death has been sequestered, Liz Stanley and Sue Wise (2011)[73] discuss Liebovitz's photographs, although they locate the pictures in the context of postmortem photography which is slightly misleading as Sontag is only dead in some of the images. They argue that, "Postmortem photography challenges binary notions of public and private 'spheres'", with Liebovitz's pictures concerning "the domestic aspect [of her] photography as a very public professional, rather than being an 'unseemly' depiction of privy moments which should remain hidden" (p957). Stanley and Wise draw on Jay Ruby's (1995) work to argue that whilst postmortem photography disappeared as a publicly recognised practice around the turn of the century, it did not vanish, but simply became a private practice.[74] Taking photographs of the dead and dying came to take on the mantle of taboo. Accordingly, they were seldom shown outside family (even individual) confines. For Ruby, the only significant difference between the nineteenth and twentieth centuries is that in the former, photographers "openly advertised and discussed the practice", whilst in the latter, such services were not "publicly acknowledged […] and customers simply stopped talking about it" (p55, p60). As Ruby suggests, the belief that "photographing the dead is always a morbid act is merely a reflection of our culturally encouraged need to deny death" (p52).

Things, however, are changing. Writing in 2002, Stanley Burns notes a growing belief that postmortem photography can be useful for the bereavement process, with some American hospitals even giving disposable cameras to families (Burns and

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[73] See also McKinney (2010) on Liebovitz's pictures of Sontag and "picturing an ethics of queer domesticity".

[74] For more on postmortem photography, see Hinkman (2011) and Burns and Burns (2002).

Burns, 2002). Reflecting this shift, in 2005, American non-profit organization *Now I Lay Me Down To Sleep* was founded. It aims "to introduce remembrance photography to parents suffering the loss of a baby with a free gift of professional portraiture".[75] I will consider their work further below. Burns also observes that, particularly in the wake of the 1980s HIV/AIDS crisis, photographers and filmmakers were turning more to the subject of death. Audrey Linkman, in the final section of her book *Photography and Death*, discusses the work of many of these artists (2011, pp154-186). It is notable how many, like Liebovitz, choose to capture the dying of a loved one, often as a means to help them comprehend and cope with their private loss. The title of Linkman's chapter – "Exhibiting the Dead" – carries a temporal framing that speaks to the relational – and power – imbalance between photographer and dying individual: they are publicly "exhibited" as other from the "living". The spectator is typically positioned to share the framing of the photographer, an interpellation that usually carries the guarantee that it is okay to look.

In 2009, the question of whether death really was sequestered still in the West was forcefully raised by the very public dying of Jade Goody[76]. However, whilst Goody's last months and weeks were captured by photographers and pictured daily in newspapers and magazines, the images were seen by some as heavily mediated. Research by Rebecca Feasey and Daniel Ashton found that members of the public questioned the photographs' authenticity, suggesting that Jade "did not look ill or dying" (2010)[77]. This reflects the careful selection of the pictures chosen and shown – of which Jade was largely in control – but also speaks to the rarity of the dying

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[75] From the "About and Mission" page of *Now I Lay Me Down To* Sleep website: https://www.nowilaymedowntosleep.org/about/mission-and-history/ [Accessed September 27th, 2012]. For a recent reflection by a photographer who works in this field, see Hochberg (2011).

[76] See especially Walter (2009). Also Walter (2010) and Woodthorpe (2010).

[77] Rebecca Feasey cited in 'Celebrity Cancer Stories' (2011). See also Feasey and Ashton (2010).

individual within the public sphere, if their actual presence can be read as a hoax rather than reality. Interestingly, there are also allegations that British tabloid *The Daily Star* digitally added a headscarf and bald scalp onto some older images of Goody to make it appear that they were taken during her chemotherapy (Brooker, 2011). That is, it was more palatable for the paper to present Jade's body in full health and fake signifiers of dying, than to publish the "real thing".

We can see, already, a faultline in the field of representability - the fragile barrier between private and public. When crossed with content that doesn't keep the dying individual – and death – safely contained within the frame, like Liebovitz's photographs of Sontag, the encounter is unsettling. Seeking to diffuse their death anxiety and restore their ontological security, the spectator may question the intent of the photographer and distributor. Typically, then, such images are circulated with the consent of the dying individual contained within the wider framing. For example, Walter Schels's very successful exhibition *Life Before Death* presented dual portraits of twenty-six individuals taken shortly before and shortly after their death. With partner Beate Lakotta, Schels spent time with each person, so that the photographs could be shown alongside quotes and biographical information. Even in spite of this, when *The Guardian* published a selection of the pictures online, some viewers said they were "nauseated" and "sickened" ('Death portraits shared around the world', 2008). Similarly, Jade Goody gave explicit permission for the many photographs of her final weeks. A large part of the framing (and wider narrative) of her dying concerned the fact that she had hired a publicist and was seeking exclusive deals so as to maximise her income before death. With Liebovitz's photographs however, no such consent from Sontag was presented (indeed, quite the reverse). Furthermore, as we saw earlier in the case of *The Mail Online* blurring a photograph of Gary Coleman on his deathbed, without express consent the dying individual may be even further mediated and effaced as a condition of visibility within the perceptual world of the living. By way of exploring these issues further, I turn now to an example that cuts across private and public boundaries.

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Fig. 14: The Walker family with their newborn baby Grayson James, taken by Crystal Brisco Photography[78]

Grayson James Walker was born at 10:00am on February 15th, 2012 at Methodist Germantown Hospital in Memphis, Tennessee. He died eight hours later. Grayson's parents Heather and Patrick had known for some months that their son would be born with a severe birth defect. As such, they knew that their time with him would be very short, if indeed he wasn't stillborn. Amongst the preparations for the birth and death of Grayson, the Walker family approached *Now I Lay Me Down To Sleep* who were able to provide a photographer to document his life. Crystal Brisco met

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[78] The full set of images is available on Crystal Brisco's website: http://www.crystalbriscophotography.com/2012/02/cherish-sweet-baby-grayson.html [Accessed September 28th, 2012]

with the family at 8:45am in the hospital and took pictures throughout the day. Heather later described Crystal as having “captured so many wonderful moments that will never be forgotten” (Walker, 2012a). Shortly after Grayson’s death, a benefit page was created on Facebook to help cover funeral costs. Some of Crystal’s photographs were shared there, with many visitors leaving heartfelt comments calling Grayson a “beautiful baby boy” and a “gorgeous lil angel”.[79]

On May 15th, the three month anniversary of Grayson’s birth and death, Heather was watching an episode of medical drama *Private Practice*. Coincidentally, it happened to feature an expectant mother discovering that her baby had anencephaly, the same birth defect Grayson suffered from. The defect means that the baby is born without large parts of their skull and brain, proving fatal in the vast majority of cases. Anencephaly is thus an utterly tragic and deeply disturbing diagnosis to receive. For Heather, the fears of the fictional mother reminded her of her own anxieties: “I remember lying in the hospital bed wondering if he was going to be alive or how long he was going to live. I wondered what he was going to look like” (James, 2012b). These reflections prompted her to share a photo on Facebook that hadn’t been shared publicly before [fig. 15]. She would later write:

> Just a few days ago, I posted a picture of my precious baby boy without his hat on. Some wonder why it took me so long to post it. Here is my answer: I was tired of trying to hide my son, the way he was, just to make others feel comfortable. I felt like people would be scared or offended because his head didn't look like other babies. A sudden impulse, in my grieving process, told me to be proud and not worried about the thoughts of

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[79] Comments left on ‘Grayson James Walker’ Facebook album. [Online] http://www.facebook.com/media/set/?set=a.248073481941775.59189.247676448648145&type=3 [Accessed September 28th, 2012]

> others. So, with one click, the photo of Grayson was posted. (James, 2012c)

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Fig. 15: Grayson James Walker, born with anencephaly[80]

Facebook responded by removing the photograph and others of Grayson for violating "community standards". They also placed a temporary ban on Heather's account, preventing her from re-uploading the pictures. Messages of support flooded in. Local - then international - media became aware of the story, ultimately resulting in Facebook restoring the image, claiming that it had been deleted in "error" (Kelly, 2012).

The above photograph of Grayson is, indeed, difficult to see. The spectator encounters Grayson alone, without the mediating and reflected affection of his parents loving gaze. With nowhere for the eye to wander, the traumatic reality of his defect is rendered all too visible. Whilst Grayson's open mouth conveys the hint of a laugh, the bulge of his broken eye and the raw red of his exposed brain scream unimaginable suffering. But this is Grayson and this is reality. Moreover, it is a necessary reality. Whilst the pictures of Grayson wearing his hat may help "others

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[80] Photograph taken from KATV news website: http://www.katv.com/story/18560143/facebook-deletes-baby-pictures-family-outraged [Accessed September 27th, 2012]

feel comfortable”, they put Heather in the position of having to conceal her son’s subjective presence and lived experience. Facebook’s reaction to the photograph’s initial publication suggests, too, that Heather’s worries “about the thoughts of others” were not entirely unfounded. Indeed, this image and others of Grayson without his hat are not amongst the twenty-nine photographs Crystal Briscoe features on her website. The picture is also lacking the “Crystal Briscoe Photography” logo which is present (and comparatively large) in all the other images. The logo acts as something of a sanction for their public display, locating them within a professional discourse that elevates the pictures beyond photographs intended for private purposes.

Now I Lay Me Down To Sleep (NILMDTS) advocate a photographic approach that eschews reality, opting to project the good death onto constructed pictures. A September 2012 newsletter suggests that photographs should be “beautifully exposed, gently retouched and converted to black & white or sepia tone”. It warns that colour “can evoke emotional reactions as well as physical reactions”, whereas black-and-white or sepia is “generally more forgiving”, citing a parent for whom “color is [a] harsh reality” which she doesn’t want to “relive” (NILMDTS, 2012). The organisation has a network of available “digital retouch artists” who use software to help make pictures more palatable for families (although they were not used in Grayson’s case). Nancy Reeves described her work retouching such images:

> When I receive these photographs, they are very harsh. […] Working with them is well beyond retouching or restoration — it is more akin to creating an image from scratch. […] Sometimes, particularly if I have partial features, I will actually paint in the missing features. (quoted in Riechters, 2008, pp2-3)

Creating photographs that can be shared – whether publicly or privately – is central to the organisation's approach. They describe their role as helping families "create photographic memories of their baby that they can be proud to share with other family members and future generations".[81] However, as we have seen, there is an artifice to how these "memories" are produced. Specifically, the organization seeks to ensure that the photographs are presentable within the field of representability of the perceptual world of the living. The specific subject at hand – dying babies – is particularly horrific and difficult to face for any grieving family. However, as was evident with Heather's wish "to stop trying to hide [Grayson] just the way he was" from people, working to sustain structures of otherness by occluding actuality may well be detrimental.

This discourse around photography and memory recollects the quote on the cover of the NHS End of Life Care Strategy: "How people die remains in the memory of those who live on." There is a suggestion that photography can offer a corrective to a "bad" death by presenting the "living" with more palatable memories. Such a notion can be observed in the abandonment and alienation the dying individual often describes before his or her death. For example, in a recent documentary, Billy Grimes, who has terminal brain and lung cancer, spoke about how he has lost contact with his "oldest friend of thirty-four years". Grimes describes how his friend "has not spoken to or seen me since I was diagnosed. He said he couldn't stand to see me ill and with no hair" (*Having the 'Last Laugh'*, 2012). This all speaks to the fears of the "living" which are expressed and projected onto the dying individual. Furthermore, this wish to absent actuality serves to

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[81] From the "Digital Retouch Artist" page of *Now I Lay Me Down To* Sleep website: https://www.nowilaymedowntosleep.org/volunteer/digital-retouch-artist/ [Accessed September 27th, 2012]

solidify an artificial barrier between public and private realms. The consequence is the creation of misleading memories based upon the perception of permissible frames of representability. This is important because, as Susan Sontag writes, “Memory is, achingly, the only relation we can have with the dead” (2003, p73). If memory, too, is regulated by the perceptual world of the living, then that which falls outside the notion of the “good death” is likely to be disavowed, whether publicly or privately. Photography has a particular part to play here. The following comments by John Berger are especially pertinent:

> What served in place of the photograph; before the camera's invention? The expected answer is the engraving, the drawing, the painting. The more revealing answer might be: memory. What photographs do out there in space was previously done within reflection. (1980, p50)

From its origins, photography - as Goldberg (1998), Gorer (1965/1995), Tercier (2005) and others have demonstrated - worked to mediate dying, sustaining a distance between the actuality of natural death and its visual representation.[82] This would come to constitute what Gorer called the “pornography of death”, where the spectacle of violent dying became far more familiar to spectators than the banalities of terminal illness. There is a spatial mediation at play here too. As we saw in the previous chapter with the exhibition photographs that were selected from news media, when the West is exposed to imagery of actual death, it is typically from overseas, whether from disasters or war zones. Alternatively, fictional representations reinforce notions of the “good” – even beautiful – death.

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[82] Photography also brought with it a shift in public/private relations. As Roland Barthes asserts, “the age of Photography corresponds precisely to the explosion of the private into the public, or rather into the creation of a new social value, which is the publicity of the private” (2000, p98)

The actual dying individual thus enters the representational frame largely to assist in private grief, or to maintain public norms. As such, the perceptual world of the living is constructed upon a fundamental socio-cultural disavowal: the lived experience, subjective presence and *agency* of the dying individual. The normative nature of this ensures that spectators readily submit to structures of otherness without questioning their own complicity in sustaining the *status quo*. This does damage not just to the dying individual, but to individual spectators. That is, in adopting the subject position of a passive consumer, rather than an active citizen, spectators disavow their own agency. I turn now to three photographic works that attempt, in varying ways, to reinstate both the agency of the dying individual and the agency of the spectator. Through them, we can theorise a coming together in solidarity which offers the possibility of political change: an unsettling of the structures of otherness which underpin the perceptual world of the living.

In 1976, Mark and Dan Jury published *Gramp*. It documents, through photographs and text, the last years of their grandfather Frank Tugend's life. The book is chronologically structured, opening with a short section of pictures of Frank and his family that offer a basic biographical overview. Then, beginning with a chapter titled "Starting to Fail: July 1970", Mark and Dan provide an oftentimes unflinching narrative which culminates in Frank's funeral in March 1974. Frank's trajectory takes him from an active outdoorsman, to an increasingly dependent dementia sufferer. Refusing to leave home, he becomes progressively weaker before slipping into a coma and dying. The text is mostly written by Mark, however included are lengthy quotes from Frank's wife, children and other relatives, as well as his doctor. Frank's mental condition renders him largely voiceless. When he is quoted, it is typically within an anecdote made to illustrate the state of his dementia. The spectator (and reader) thus encounters Frank through a framing that strips him of much agency in the process. Moreover, there is no indication provided within the book that the project is consensual, let alone whether Frank was aware – or indeed, could be aware – that some of the photographs would become public. Instead, Dan and Mark's introduction offers an alternate framing, writing that "we learned a lot about Gramp, and about one another", however "all of us […] learned even more about ourselves" (Jury and Jury, 1976, p*viii*).

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Fig. 16: From the back cover of *Gramp* (Jury and Jury, 1976)

The book's back cover provides a further framing, with Frank becoming infantilised in his guise as dying individual [fig. 16]. Coupled with this is the inclusion of pictures that are oftentimes troubling in their starkly honest content. Frank lived in his own room over the final months, which is where he increasingly spent his time, withdrawing from family. The room itself was barren, containing just a chair, cabinet and bed, on top of which sat an often uncovered mattress, rife with stains. Frank's difficulty with incontinence is tackled across a series of images. He is pictured sat on newspaper, placed there by his wife to protect the carpet from excrement (pp90-91), as well as a sequence of three images where Frank is bent over his bed whilst grandson Dan cleans his backside (pp114-115). Other pictures show Frank naked, sat on the toilet after having soiled his underwear, then later in the shower about to be scrubbed by his daughter Dee (pp92-95). The photograph of Dee preparing to help Frank clean himself is particularly interesting [fig. 17]. She looks directly at the spectator, communicating a strong sense of uncertainty. Her posture is also awkward. However, in the background (and the bath) Frank seems perfectly content and able. If Dee was removed from the picture, the sense of unease it instills would disappear.

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Fig. 17: Photographs from *Gramp* (Jury and Jury, 1976, pp94-5, p109)

There is a marked absence of interpersonal family engagement with Frank, particularly in the photographs of his final year, beyond the performance of duties such as shaving or feeding him. Many of the images further inscribe a lack of intersubjectivity through capturing encounters where Frank is distant and different. In one, Frank's granddaughter Hillary holds her grandmother's hand as the pair stand several metres away from him [fig. 17]. In another, Hillary and her mother are sat reading on a couch, whilst next to them Frank sleeps (pp80-81). A similar photograph shows Frank, again asleep, sat in the background whilst family members, including a baby, play in the foreground (pp118-119). This composition is mirrored in the book's final image of Frank. He is pictured lying in his open coffin, located at the back of the photograph, whilst the same baby crawls on the floor in front (p146). The infant, here, guarantees the continuation of life after death, helping assuage any spectatorial concerns about the absolute finality of Frank's existence, whilst also redirecting their gaze towards notions of new beginnings.

Speaking about the book to local paper *The Milwaukee Journal*, Frank's daughter Florence revealed her concerns that the publication of such intimate, often intrusive, images could "discredit" him publicly. However, she adds: "I have read letter after letter from people saying the book has helped them with their old folks, so I feel better about it" (quoted in Dulles, 1976, p6). This is an interesting insight into the book's reception: the living – or rather, "not-dying" – individual gaining insight and familiarity in how to deal with the "dying individual". Taken together, the overall framing works to exclude the dying individual, or rather, to construct them as a "flawed citizen". They are positioned almost as an object, outside the familial community of the "living".

In an afterword, Mark writes that he and Dan "photographed [Frank] as a way to pass the time" whilst they were "babysitting" him. He adds that "long after" their grandfather stopped recognizing them, Frank nonetheless "recognized that the person with the camera was a friend, and he would stay close to whoever had the camera" (Jury and Jury, p151). We find here, then, an admission that in many respects the camera had become a companion. This comes with the very real risk that, from the spectator's perspective, Frank is reduced to object status. Indeed, the book treads a curious line. On the one hand – particularly in 1976 when it was published – *Gramp* seeks to make the many indignities of dying familiar to a wide public. Equally it works to restore dying and death to the banal everyday. However, in doing so, it loses something of Frank as an *individual*, who seemingly suffers social death within the course of the book. Nevertheless, this in itself is revelatory. It renders visible what is largely unseen within the perceptual world of the living, raising many questions about how the notion of the good death and how the dying individual is – and should be – encountered. *Gramp* is unsettling and it is notable that there are very few books like it. Ultimately, though, the assorted framing devices work to provide an explanatory overlay so that death is kept safe and contained. Here, Pier Paolo Pasolini's comments on death and narrative are pertinent:

> Death effects an instantaneous montage of our lives [...] transforming an infinite, unstable and uncertain - and therefore linguistically not describable - present into a clear, stable, certain, and therefore easily describable past. (cited in Rascaroli, 2009, pp9-10)

Whilst *Gramp* exists as a fixed text, *The Dad Project* is photographer Briony Campbell's ongoing attempt to present publically not just her father and his dying, but her own struggles with grief, memory and representation. David Campbell, a renowned psychotherapist,[83] died of bile duct cancer in September 2009. Over the proceeding months, his daughter, then undertaking a graduate course in photography, worked to document the experience as a shared project.

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[83] An obituary in *The Independent* describes David as "one of the most respected and influential family therapists in the UK, with an international reputation as a writer, editor, trainer, consultant and clinician" (Burck, 2009).

Fig. 18: Briony Campbell and her father. From *The Dad Project*.[84]

To date, the photographs and video Campbell took have been seen publicly in a book, exhibitions, a short film, newspapers and magazines, and also a website. Campbell's intent with the work is very much concerned with facilitating "emotive responses" from spectators, which can then foster "bigger dialogues", working towards shared and interpersonal insight. This is a structural part of the project, which Campbell regards as having two "chapters". The first, she notes, "belonged to dad and me", whereas after "it had been exhibited and published" it "belonged to whoever saw it" (Campbell, forthcoming). The personal – and taboo – subject matter also brought certain questions around photography practice to the fore. Campbell writes:

> Every documentary photographer is seeking to reveal truths, but telling another's story truthfully is essentially impossible. If I chose to tell the story of losing my dad I would be telling *our* story; my dad and me - therefore it would be true. Maybe I would be liberated of the eternal and integral problem of the documentary photographer… (*ibid*.)

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[84] All photographs reproduced here are available on Briony Campbell's website: http://www.brionycampbell.com/projects/the-dad-project [Accessed September 28th, 2012]. However, Campbell has exhibited many more than are on the site.

The footage and photography Briony Campbell presents of her dying father in *The Dad Project* is offered (and constructed) as consensual: her deeply personal framing (re)assures the spectator that it is okay to watch. This is also very much a project about "Dad" not "David". Campbell's focus is interpersonal relationships, not individual biography. We thus learn little about David's professional accomplishments and acclaim.

Fig. 19: Briony Campbell photographs her dying father in *The Dad Project*

In an interview, Campbell notes that she sought to capture "love", rather than "angst", and as such avoided "ugly, painful and dark" images. She adds, "if it was a painful moment then I tried harder to make the picture aesthetically beautiful".[85] Indeed, Campbell's use of light (particularly natural light) and the colour white in her compositions adds an almost transcendental texture to *The Dad Project*. An image of her father being taken into an ambulance is flooded by sunlight, his neck and upper torso dissolving into abstract form [fig. 19]. In contrast, the ambulance driver's face is captured more clearly, yet his gaze is confusing. He looks over

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[85] "I take pictures I am compelled to take…". Video interview with Briony Cambell by the Open College of Arts. Available online: http://www.weareoca.com/photography/i-take-pictures-i-am-compelled-to-take/ [Accessed September 28th, 2012]

David's head towards an unknown location. Another photograph of her father in his garden is overwhelmed by sun. The spectator's eyes are forced to retreat down towards the couple, who are physically together, but separated, facing different directions. Both pictures recall the oft-cited seventeenth-century maxim by Rochefoucauld, "You cannot stare straight into the face of the sun, or death."[86] In these pictures, the spectator is encouraged to find David – the face of the dying individual – outside the sun's glare and, more importantly, death's frame.

Fig. 20: Spilled milkshake. From *The Dad Project*

The overall absence of "ugly" imagery is perhaps captured most starkly in the photograph of a spilled milkshake [fig. 20]. Against the stone colored linoleum of a kitchen floor, the splashes of thick, red, liquid look much more like blood than a beverage. Indeed, the "correct" reading is difficult to achieve, despite the explanatory text.[87] The wider framing of the project, coupled with its overall aesthetics, encourages a reading of abject bodily fluids shed as the consequence of

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[86] 'Maxim 26', Francois de la Rochefoucauld. Cited in Yalom, (2008, p*v*)

[87] On her website, Briony Campbell adds the following underneath the photograph: "I couldn't be a photographer when this happened, I was a daughter. After I'd swept up the glass I paused, for what felt like a long while, before managing to photograph the milkshake stain. Perhaps I'd proved (to myself or my parents? I'm not sure which was the necessity) that I was a daughter before a photographer" (Campbell, n.d.).

some indeterminate, yet horrific, incident, rather than a simple domestic spillage. This misreading of the milkshake speaks, I feel, to the linkage of death and violence which is how dying is mostly encountered in visual culture. Moreover, as all is not being said within the frame, the spectator is forced to ask questions. For Campbell herself, the picture was a "turning point" in the project. Her father had dropped his energy milkshake, but "she couldn't bring [herself] to photograph the moment as it occurred", thus making her dual role "suddenly explicit". In consequence, Campbell came to realise that, for her, "what I hadn't captured was as relevant to our story as what I had", therefore "the fact I couldn't shoot everything was the story" (forthcoming).

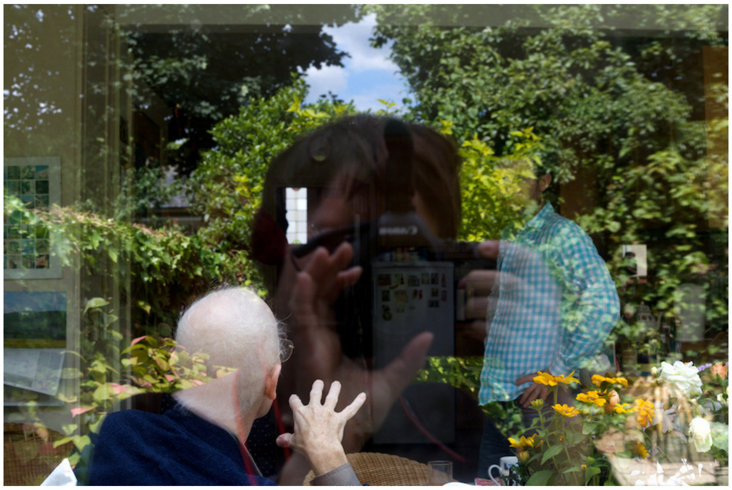

Fig. 21: "Family Portrait". From Briony Campbell, *The Dad Project*

Campbell rarely shares the same frame as her father. When she does, it is often to comment on the structural distance her camera creates. In one image, her face, covered by a camera, is reflected on a window [fig. 21]. This produces an illusion wherein her father appears to be looking at her taking the photo, yet in actuality he is addressing somebody within the room where he sits. Campbell here captures herself in the process of creating the photographic frame of which she is inescapably a central part, yet nonetheless, the act of photographing keeps her apart from her dying father. Campbell has described the dual roles she found herself performing. She writes of feeling “resigned to the fact that documenting [my] dad's death was as instinctive to me as experiencing it,” adding that this triggered both pride in demonstrating an “innate” photographic ability, and shame that she “was thinking so objectively” through such an emotional time (*ibid.*). These struggles articulate a tension between Campbell’s presence as both companion and camera to her father’s passing, a binary she punctures in the project through the inclusion of self-portraiture. Campbell’s willingness to enter the representational frame she otherwise constructs – not to mention her tangible sadness and supportive presence – adds a personal, subjective texture to the lens through which her dying father is encountered, shielding the spectator from concerns that she was clearly wrestling with.

The spectator is further shielded through Campbell’s conscious mediation of the subject matter. It is significant that the picture which perhaps asks the most questions and most unsettles the frame – the spilled milkshake – captures the moment where Campbell fully realised her role in producing the field of representability, yet it features neither her nor her father. The picture speaks especially of the difficulty in being both camera and companion to the dying individual and possibly came to inform Campbell’s decision to ensure that where she did photograph painful moments, they would be “aesthetically beautiful”. *The Dad Project* can thus be regarded as something of a counter to *Gramp*, where many difficult pictures of Frank were included. Ultimately, however, both operate in similar ways. Whilst Frank is objectified through his family’s camera, David’s subjectivity is mediated through Briony’s careful framing. Both enable the dying individual to enter, much more completely, the perceptual world of the living, but at the same time, they protect the spectator from their own complicity in sustaining the socio-cultural *status quo*. This largely stems from the fact that neither photographer is a neutral party, ensuring that the spectator encounters Frank and David through a family frame in their attempt to make typically private affairs public. Both also orientate the spectator's gaze towards the dying individual as one of compassion, or perhaps pity. This facilitates sympathy, but not solidarity.

Laura Tanner's (2006) work on "terminal illness and the gaze" can help us see the problem with this more clearly. In a section on "sympathetic seeing", Tanner suggests that "the gap between the living and dying" can only be bridged though "a radical and almost contradictory unsettling of power relations". For Tanner, this imbalance in power relations is most pronounced as a consequence of the spectator's subject position as "healthy", rendering them potentially unwilling to "acknowledge their own mortality". She advocates for a "sympathetic gaze", wherein the spectator looks "with an unflinching, directed gaze", even if they find such an "intrusive" stance "embarrassing" or "disturbing" (2006, pp25-26). Whilst I agree with Tanner in part, I find aspects of her formulation problematic. Firstly – and perhaps most seriously – Tanner accepts a simple distinction between "living" and "dying", rather than regarding dying as simply a phase within living. Secondly, her notion of "healthy" is limited to physical determinants, failing to encompass the social, psychological and existential health of the dying individual (whilst also assuming the spectator can never be "unhealthy"). Thirdly, her "sympathetic gaze" seems to stop at recognition, which renders it an introspective gaze – I am mortal too – rather than an interpersonal one. Put another way, dying individuals gain agency only through what they provide to the spectator.

Instead of sympathy (or compassion, or pity) towards the dying individual, what is necessary to restore agency is *solidarity*. This, however, comes with certain caveats. Or rather, this needs to be formulated within the context of spectatorship and citizenship that I have been outlining in the contemporary perceptual world of the living. As Lilie Chouliaraki (2011) has noted, “solidarity”, which she defines as “the imperative to act on vulnerable others without the anticipation of reciprocation” (p364), has been appropriated in the West over recent years by the forces of capital. Chouliaraki outlines the dominant mode of “solidarity” in discourse today as “ironic”. She argues that “ironic solidarity” works by “rendering public our expressions of solidarity to vulnerable others while privatizing the question of why we should be in solidarity with them” (p370). Calls for such “ironic solidarity” are carefully mediated to exclude “visions of social change” (p371) and challenges to structures of otherness. Moreover, they typically position the self “at the heart of the communicative structure” (p370).

Clearly, the “solidarity” I am advancing is different. It accords far more with the “solidarity” Chouliaraki seeks which is concerned with “the communication of human vulnerability as a political question of injustice that can become the object of our collective reflection, empathetic emotion and transformative action” (p377). It is precisely this “political question of injustice” which is missing from the positioning of *Gramp* and *The Dad Project*. It is also absent from the photographs in the “Saying the Unsayable” exhibition considered in the previous chapter. However, in considering that exhibition, the potential for solidarity between spectator and dying individual was seen through Azoulay’s “civil contract of photography”. By *watching* – that is, by both posing situational and temporal questions of the photograph’s content *and* recognizing that neither spectator, photographer or photographed person holds a monopoly over meaning – the spectator is decentered from their position of privilege. Their stance is not one which can accommodate a sympathetic gaze precisely because, in rejecting complicity in submitting to structures of otherness, it is unsettled to its core. Instead, through regarding the dying individual as an equal citizen, the spectator fosters solidarity against the grain of the frame, albeit with no guarantee that a complete picture is forthcoming. Susie Linfield captures well the necessary shift from looking *at* to watching, which comes from the spectator's rejection of a totalising gaze and acceptance of a subject position that lacks mastery over the individual image:

> In approaching photographs […] the point is not to formally disassemble them as a way of gaining mastery; nor to reject them as feeble, partial truths; nor, certainly, to deny the sometimes uncomfortable, sometimes unfamiliar reactions they elicit. […] [By] connecting these photographs to the world outside their frames, they begin to live and breathe more fully. So do we. Instead of approaching these images as static objects that we either naively accept or scornfully reject, we might see them as part of a process – the beginning of a dialogue, the start of an investigation – into which we thoughtfully, consciously enter. (2010, pp29-30)

Given the subject matter under discussion, such a stance can be helpfully placed in contrast with Michel Foucault's (1973/1994) notion of the "clinical gaze". For Foucault, modern medical discourse was founded upon the site of the corpse and the role it played in training doctors. Interestingly, the literal definition of "autopsy" is "the act of seeing with one's own eyes". Through dissection and examination, the individual is stripped of subjectivity and rendered as an object for scrutiny. The "clinical gaze" stems from this tendency – supported by institutional structures – to view the (dying) individual as a body who can only be known through a rational, totalising lens. This gaze, Foucault writes, works towards "absorbing experience in its entirety, and [...] mastering it" (1994, p*xiv*). More than anything, it seeks to master death and keep if safely contained within a framework. The perceptual world of the living currently tries to frame the encounter with the dying individual through such a gaze. Challenges to such structures of otherness in visual culture – such as *Gramp* or *The Dad Project* – often still position the spectator as central, still in a stance of mastery. Put simply, they provide a corrective – creating familiarity with the dying individual and encouraging greater compassion towards them – but they don't challenge the spectator's complicity in submitting to structures which keep the dying individual as different. I turn now to Lori Waselchuk's photographic project *Grace Before Dying* (2010) as a text that is willing to unsettle the spectator by way of fostering solidarity with the dying individual – and all that entails.

Fig. 22: From *Grace Before Dying* (Waselchuk, 2010, pp64-65)

Lori Waselchuk's *Grace Before Dying* consists of pictures taken over a two and a half year period at Angola maximum security prison's hospice program.[88] Angola is Louisiana's largest jail, in a state where 1 in 55 citizens are in prison. Three-quarters of its all-male inmates are serving life sentences. The hospice program was introduced to the prison in the 1990s and helps deal with the consequence of the 550 percent increase in inmate deaths between 1983 and 2010, which occurred as a result of an ageing population (Powell, 2010). As such, *Grace Before Dying* captures an institution (the hospice) within an institution (the prison) where the dying individual is always already a flawed citizen as a consequence of his prisoner status. (There is also the inescapable layer of race – and racism – given the overwhelming percentages of inmates who are not white.)

Vibrantly colourful images of remembrance quilts made by prisoners open and close the book, but Waselchuk's photographs are otherwise entirely black-and-white. Whereas *Gramp* and *The Dad Project* present the dying of one individual, *Grace Before Dying* offers a much more divergent narrative. The final section of the book is wholly focused on the elaborate and ornate funerary arrangements provided for inmates (pp88-111). It is in the preceding pages where we encounter the dying individual, or rather, the multiple individuals who occupy the hospice program, whether patients, health workers, or the many prisoner volunteers who ensure that the dying individual has a companion at all hours of the day until their death. A tangible sense of companionship – and authentic camaraderie and interpersonal support – pervades the photographs. Many pictures capture deeply intimate moments of tender friendship. A particularly poignant image shows four men each working to reduce the swelling on different limbs of their dying friend Richard

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[88] The photographs have also toured as an exhibition, accompanied by quilts made by volunteers at the hospice. See the *Grace Before Dying* website for more details: http://www.gracebeforedying.org/ [Accessed September 28th, 2012]

Liggett (pp48-49). The photograph on the following pages of the book pictures the moment where Richard's fellow inmate Paul Krolowitz said his final goodbye with an all-encompassing, but gentle hug. The accompanying text quotes Richard as saying, "You were the best friend I ever had. I love you." Paul replies, "I love you too" (pp50-51). Such frank and tactile exchanges of friendship and homosocial bonding are all the more moving not just because they are occurring between men, but between men who, as a consequence of past actions, are perceived by the maximum security institution – and the state – as potentially violent and remorseless.

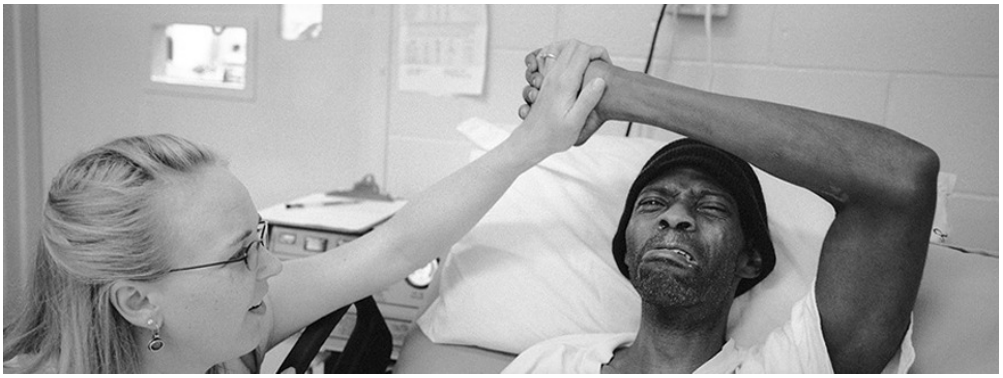

Fig. 23: From *Grace Before Dying* (Waselchuk , 2010, pp52-53)

Whilst not irrelevant, the spectator is oftentimes extraneous in such images. Waselchuk's skill as a photographer, assisted by the longevity of the project, means that aside from artful composition, her presence is not felt. This is not to absent her role, but rather to contrast it with the familial mediation seen in *Gramp* and *The Dad Project*. She is also not afraid to confront the raw and the real. Hospice patient Timothy Minor, unable to speak as a consequence of his condition, is seen in two photographs that present only the surface of his suffering [figs. 22 and 23]. In one, he is with his friend Felton, who "stays with him eight hours a day, seven days a week" (p55). Timothy's arm goes out to connect with Felton's, but his face is pained and focused ahead. Any connection he is making seems strained and painful. In another, he appears in great agony and sadness, his composure contrasted by the kind, encouraging face of his nurse Melody. The calm warmth of Melody's gaze appears somehow inadequate, somehow failing to fully respond to Timothy's clear difficulties. The expressive contrast suggests a near unbridgeable gap, yet such separation is undermined by the holding of hands. The wide frame of both photographs further frustrates the connection between Timothy and his respective companion. As a consequence, the spectator is given no quick and easy comprehension of the image. To focus on the companion is to ignore the dying individual; to focus on Timothy is to open up a multitude of questions which the images and accompanying text raise but barely answer.

Fig. 24: From *Grace Before Dying* (Waselchuk, 2010, pp32-33)

We only encounter hospice patient Albert Soublet in one photograph [fig. 24]. He is pictured being lifted out of his wheelchair, so he can pass through a security checkpoint. Helping Albert are hospice volunteer Nolan Janes and fellow hospice patient Kenny Mingo. Prison guards stand at the side of the corridor, looking on. This photograph captures three conflicting looks. Albert stares directly at the camera, thus reminding the spectator of the photographer's presence, which has been otherwise invisible. It is hard to ascertain whether he is looking simply because his head needs to be in that position to facilitate the lift, or whether Albert is intentionally stating his agency against the perception that he is just a body to be looked at and done to. Kenny, the second dying individual in the image, is situated behind Albert, holding his wheelchair steady. Gazing downwards to monitor the move, Kenny's face is one of focused concentration and concern. Whereas Albert appears rather relaxed, Kenny is flush with worry. The text accompanying the image gives a short anecdote about how Kenny had recently let another patient take his room in the hospice. Kenny is quoted as saying, "When I looked at him, I saw myself" (p33). The third look pictured in the photograph – that of the female prison guard – appears rife with an unsettled tension. With a couple of metres separating them, she stands with her arms by her side, behind and to the right of the three men. She is distanced further through a multitude of markers: race, gender, age and status as "living". Moreover, as a guard, she is institutionally (and ideologically) constructed as being in a position of authority over these three prisoners (and two dying individuals). Yet she is detached and distant, rendered unable to act.

These three looks are spatially connected: the guard stands straight but her eyes appear turned to look at Kenny, who is looking at Albert, who is looking at the spectator. If the spectator tries to seek refuge from the challenge of Albert's direct gaze by glancing towards the guard, they are returned to Albert through her unsettled gaze. At every stage, the unknowableness of each individual is overwhelming. What is clear, however, is the contrast between the guard and Kenny, with Albert's look perhaps forcing further contemplation of the relations between institution and dying individual. The photograph would be radically different without the guard. Of the three faces we see, she is the only one who is identified as “living” (that is, “not-dying”) as well as the only individual who is a full citizen. However, whilst she is physically – and ideologically – “healthy”, the uncertainty of her stance suggests that something is lacking. Unlike the three men, her name is never revealed. As such, her presence acts as something of stand-in for the spectator, also typically constructed as an anonymous “living” citizen. But rather than present a stance of mastery, the guard seems troubled by her position, thus unsettling the spectator’s own subject position still further.

The book in general – and this photograph in particular – captures moments of great interpersonal support and communal togetherness occurring in full public view within the prison, yet, to the world outside, occurring behind the private walls of an institution. The guard (and the spectator) is granted access to both realms, and thus forced to react to one with the knowledge of the other. The photographs thus unsettle and undermine the field of representability which typically governs the perceptual world of the living. The wider carceral framing – encompassing even the hospice – casts society’s framing of the dying individual into sharp and troubling focus. Moreover, as Linfield argues, “It's not what's in the frame or what’s outside the frame that matters most: it’s in the relation between the two that the meaning and strength of documentary photographs can be found” (2010, p201). The spectator, by being placed in a position of continual oscillation, is forced to constantly confront the questions that *Grace Before Dying* poses when the photographs are rubbed up against the frame of the perceptual world of the living. There are no ready answers. It is the process itself that matters. Rather than offering the spectator a position of instructional mastery over death, the photographs instead leave the spectator questioning what such mastery means and who suffers as a consequence of its attainment. In so doing, they foster solidarity in the encounter between spectator and dying individual; a solidarity based not on compassion, or pity, but rather the recognition that structures of otherness are working to keep the encounter always already foreclosed.

In *Gramp*, the starkness of the photographs seemed to show an absence of love, whilst in *The Dad Project* Briony forged it through light and beauty.[89] By contrast, *Grace Before Dying*, captures "love" as central and structural. The text in *Grace Before Dying* (2010) is filled with vocal statements of "love". Felton speaks of how "much [Timothy] loves me" (p65); a hospice volunteer says of a patient, "I want him to know that I love him like a brother" (p75); a different volunteer talks of how, spending time there, "you grow to love your patients" (p37); another is quoted as saying, "Love is a monster. Love is a big thing, a big ol' thing" (p82). Such public – rather than private – expressions of love reveal openly the foundations upon which the community is built. As Emmanuel Levinas argued, "what we call, by a somewhat corrupted term, love, is *par excellence* the fact that the death of the other affects me more than my own" (2000, p105). The perceptual world of the living is, however, currently structured to convince spectator and citizen alike that their own death – indeed, their potential immortality – is central. Contemporary fields of representability work to ensure that any encounter with the dying individual is carefully mediated and constructed as different. This is a fragile (and facile) arrangement, meaning it can be easily unsettled and punctured. It just requires the spectator to be willing to reject a stance of mastery and accept – or rather, welcome – uncertainty. Levinas once asked, "Is there no thinking that goes beyond my own

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[89] Thanks to Michele Aaron for this observation.

death, toward the death of the other man (*sic*), and does the human not consist precisely in thinking beyond its own death?" (quoted in Robbins, 2001, p126). The following chapter poses this question to the spectator to consider their *responsibility* in the encounter with the dying individual. Specifically, it asks whether there can be an ethical preface to spectatorship: a space where the fields of representability that govern the perceptual world of the living are challenged. I will examine this question through feature length films, where the spectator's subject position is most fixed and the Spectacle is at its strongest.

CHAPTER FOUR

SCREENING THE DYING INDIVIDUAL:

FILM, MORTALITY AND THE ETHICS OF SPECTATORSHIP

> When this device is made available to the public, everyone will be able to photograph those dear to them, not just in their immobile form but in their movement, their action, and with speech on their lips; then death will no longer be absolute.
>
> - La Poste (Paris), 30th December 1895[90]

> Whoever one films is growing older and will die. So one is filming a moment of death at work.
>
> - Jean-Luc Godard (1986, p181)

> "They pay you to die in public?!"
> "To die young in public."
> "Sorry, I'd rather die poor and private."
> "You can't."
>
> - dialogue from *Death Watch* (1980)

Bernard Tavernier's 1980 film *Death Watch* posits a near-future where dying "the old way" – through terminal illness – has become a rare event. So rare, in fact, that its presence is seen as suitable subject matter for a media event. When Katherine (Romy Schneider), a middle-aged woman, is given just two months to live, a television network launches 'Death Watch', a reality show following her every movement. Briefed to befriend Katherine, journalist Roddy (Harvey Keitel) permits a camera to be implanted in his brain, allowing continual covert filming of everything he sees. Whilst shying, then running, away from the overt public spotlight placed upon her, Katherine is inescapably captured and framed by Roddy's

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[90] Quoted in Arthur (2005, p24)

gaze: as camera and companion he invades her private space so she can be screened for the entertainment, edification and education of television spectators.

What is most absent – and least understood – in this alternate public sphere is terminal illness. As one journalist tells Katherine: "[We need] to come close to someone dying. There's a certain sad fame about it, in dying the old way. Not in flames, or in a crash, or abroad in war ... we've had that up to here. But in the way … forgive me … the way it's happening to you. We miss the real thing." The dying individual has become so unseen a being that their existence needs to be captured and broadcast. And thus mediated, framed and screened. "Why?" Katherine asks. "We need it," she is told.

Fig. 25: Roddy watches (and films) Katherine on television in *Death Watch* (1980)

As we have seen, in the West, barriers of taboo and unfamiliarity have resulted in dying being screened from view and regarded as "a deviation from the social norm" (Elias, 1985, p69). However, death was (and is) structurally central to popular entertainment, none more so than in the cinema where it has sustained a visual, often visceral, presence (see Aaron, forthcoming; Hagin, 2010).[91] Here, of

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[91] Vivian Sobchack sees a "kindness" in screen violence where, through form and style it "creates some kind of order and meaning" which can help make sense of the random violence in the real world. (1976, p93)

course, the dying individual is screened *for* public view. Central to the public projection of the dying individual is Geoffrey Gorer's (1965/1995) concept of "the pornography of death". Writing mid-century, he saw that whilst "the natural processes of corruption and decay [had] become disgusting […] violent death has played an ever growing part in the fantasies offered to mass audiences" (pp20-21). As such, the spectacle of death displaced the natural actualities of illness and the everyday banalities of dying (see also Tercier, 2005, pp210-15).

Geoffrey Gorer's "pornography of death" thesis is especially pertinent to *Death Watch*. At one point, the television producer even opines: "Look how shy we've become about death – it's the new pornography". My interest lies in *Death Watch*'s suggestion that this is not a dystopic projection: that whilst "we miss the real thing", we seek it out in spectacle, not actuality. Whilst the specifics of *Death Watch* remain, thankfully, science–fiction – although the recent case of Jade Goody's very public dying suggests the prescience of Tavernier's text – the film raises, for me, several significant questions about how the dying individual is encountered in contemporary Western media. Furthermore, it asks for whose benefit the dying individual is seen and screened. If our formative encounters with dying "the old way" take place on screen in typically fictional figurations, what are the ethical and political implications of this? Moreover, what is the *responsibility* of the spectator towards the actual dying individual in such a situation?

Terminal illness films typically wed dying to a narrative which, in its continuity and linearity, offers comfort. In restoring the otherwise absent social, psychological and existential aspects of dying, cinema suggests that death can be meaningful. Whether dying spans the entire narrative, or serves a more specific purpose, physical and bodily realities are mostly absent. Dying in film normally ends with a romanticised and idealised death-bed scene and so grants the possibility of a "good death". As Fran McInerney observes in her survey of such films, "Cinematic dying, enacting the narrative imperative for a 'happily ever after', promulgates passivity, linearity, beauty, resolution and salvation in the face of mortality" (2009, p213).

At the time of *Death Watch*'s production, questioning taboos around dying had particular cultural currency, encouraged through the popularity of books by Elizabeth Kübler-Ross (1970), Ernest Becker (1973) and others. Indeed, the cultural resonance of such texts in the West is immortalised in a scene from *Annie Hall* (1977) where, early in their relationship, Woody Allen's character Alvy buys Annie both Jacques Choron's *Death and Western Thought* and Becker's book.[92] In 1979, Hollywood went one step further. Bob Fosse's Oscar winning film *All That Jazz* (1979) turns Kübler-Ross's "five stages" theory of dying into a series of musical numbers.[93] Whilst its spectacular exuberance is atypical of most films about dying, we can view the climax of *All That Jazz* as analogous to the filmic encounter between spectator and dying individual.

Joe Gideon, a choreographer and theatre director, has become incapacitated through illness. He is coming to terms with his approaching death by mentally projecting musical set pieces, each dealing with one of Kübler-Ross's five stages. The climax is prefaced with Gideon alone and recumbent on a hospital bed. His hands have been strapped to the side rails to prevent interference with the equipment. Gideon looks upwards, his gaze resting on the jagged green graph on the

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[92] Testifying to the number of recognisable titles about death, in the original screenplay to *Annie Hall* Alvy buys himself Becker and Choron's book and gives Annie "something by Kübler-Ross" and Tolstoy's *The Death of Ivan Ilyitch* and (Hall and Brickman, 1976, p51).

[93] Kübler-Ross's "five stages" – denial, anger, bargaining, depression and acceptance – derive from her interviews with dying patients and were first expressed in her 1969 book *On Death and Dying*. The stages commence when the dying individual is diagnosed with a terminal condition. Whilst they chart a linear path, Kübler-Ross notes both that stages can occur out of sequence and also that any given individual may not go through them all. The validity of her model has, however, long been challenged (e.g., Kastenbaum, 1995, pp104-108)[93], but this has done little to dent its immense and lasting cultural appeal.

screen monitoring his heart. He replaces this, mentally, with a television screen [fig. 26]. Eventually the entire filmic frame is comprised of Gideon's mind's eye[94], as he envisions one final number. Having passed through denial, anger, bargaining and depression, Gideon, with this last song and dance routine, has finally reached acceptance.

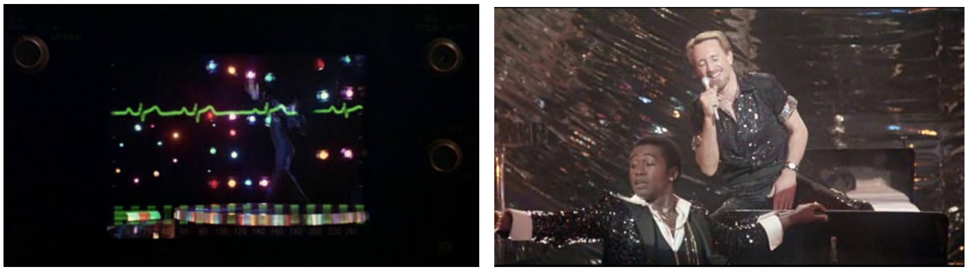

Fig. 26: From the climax of *All That Jazz* (1979)

From a fantastic, phantasmic silver stage, the terminally ill figure of Gideon sings "Bye Bye Life" to an audience of family, friends, acquaintances, enemies and medics. Gideon is accompanied by showman and soulful troubadour O'Conner Flood, seen earlier in the film as an individual indicative of showbiz insincerity, symbolising the vacuity and hollow fraternity lying behind the shiny screen of the entertainment spectacle. Here, however, as conjured by Gideon, Flood varies his obsequious routine patter. Gideon is introduced as a "so-so entertainer" who "was never nobody's friend" making "his final appearance on the great stage of life".

The initial gentle intonations and measured movements of the pair slowly escalate into an all-out showstopper [fig. 26]. Where Gideon sings "I think I'm gonna die" and "bye bye my life goodbye", Flood echoes "I think he's gonna die" and "bye bye your life goodbye". Two female dancers accompany their routine wearing white skin tight body suits, adorned with faux veins and arteries [fig. 27]. The audience claps along. As the number builds to a crescendo, Flood starts to

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[94] What Bruce Kawin (1978) has termed "mindscreen" narration.

dominate the singing. Gideon’s vocal agency is replaced by increased physical liberation: he rushes into the audience, ecstatic, sharing farewells with everyone. Returning to the stage with rapturous applause, Gideon concludes the duet atop a silver dais. As he vocalises the final “goodbye”, the musical accompaniment is punctured by the non-diegetic beeps of a heart monitor. Gideon's body is plunged into darkness as the audience erupts in cheers. The crowd settles.

Fig. 27: From the end of *All That Jazz* (1979)

The camera frames Gideon’s face as he is carried forward on a silver conveyor belt towards the angelic female figure (and smiling face) of death. Happiness washes over Gideon’s sweat-drenched visage. The soundtrack reprises “Bye Bye Life”. The shot, positioned from death’s perspective, ends with an extreme close-up of Gideon’s eyes. Suddenly, there is silence as we cut back to actuality: Gideon’s corpse is enclosed in a body bag. As his head is sealed in, only the rip of the zipper is heard [fig. 27]. The camera moves in to capture a final close-up, but his face is permanently occluded through the opacity of the plastic.

Whilst anchored in the hallucinatory excess of fantasy, this entire sequence, I suggest, mirrors the typical cinematic encounter with the dying individual. Indeed, it is not much less absurd than the end of *Dying to Talk* (2012), discussed in chapter two, which is used as a film to aid in public death education. The irreality of *All That Jazz* helps reveal a dynamic which is typically disavowed: the spectator’s pleasure is wedded to the dying individual's terminal decline. The dying individual is offered up by the Spectacle ("sacrificed" would be too strong a term here, although not wholly inappropriate) to provide the spectator with certain assurances: death can be comprehended *and* made meaningful *and* contained within a framework. The Spectacle, that is, offers securities which actuality can't provide.

At its core, Gideon's final routine is an act of wish fulfillment. The on-screen spectacle he conjures offers comfort and moral solace unencumbered by the reality of his suffering and abandonment. Within the diegesis of the fantasy, Gideon is given closure and meaning by accepting his mortality and recognising that life will continue without him. Looking more agile and dynamic than ever, Gideon, centre stage, gets to say goodbye to all the people he has ever known, before sliding serenely towards the warm, comforting figure of death. But more than this: there is no pain or discomfort; no iota of suffering; only jubilant celebration and the possibility of something beyond. And more: this final "act" concludes a narrative arc (broadly, that of the film; specifically, that of Kübler-Ross's five stages) which offers the promise of a good death: structured, knowable, predictable.

Bracketed away from actuality, the musical number is a fantastic projection of individual anxieties which are reworked and then rendered safe upon the appealing sheen of the screen. The reality – the banality, the triviality, the waiting, the human – is rejected in preference of spectacle. The anxiety being quelled, specifically, is death anxiety. As Irwin Yalom argues, "Death anxiety is the mother (*sic*) of all religions, which, in one way or another, attempt to temper the anguish of our finitude" (2008, p5).[95] In turning to fantasy and away from actuality, Gideon is able

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[95] See also Yalom (1980) and Lifton (1980).

to physically reframe all his concerns (his suffering; his isolation; his death) by constructing and embracing a world wherein these anxieties cease to trigger unease.

In seeking to shore up our "ontological security", terminal illness films perhaps function as spectatorial salves. Spectatorship offers a safe space for the social taboo to be transgressed, whilst concurrently granting the temporary quelling of individual death anxiety. Which is to say that "we need" the moral solace offered by the sacrificial spectacle of the dying individual. Through such, the perceptual world of the living can continue to keep the actualities of dying – and the actual dying individual – separate and segregated from the public sphere. Indeed, fictional dying helps to perpetuate the notion of the "good" death. Filmic texts are typically structured to ensure this dynamic is disavowed. In so doing, they perpetuate myths of individualism, whilst also preying on and placating the spectator's death anxiety, sanctifying the screen's ersatz morality in the process of restitution. In succumbing to the temptations of the Spectacle, the spectator adopts and accepts the selfish promises and pleasures of spectatorship over the politics and responsibilities of citizenship. As we have seen in previous chapters, this has real social impact.

The quotation by Emmanuel Levinas that closed the previous chapter indicates the direction we are headed.[96] He asked, "Is there no thinking that goes beyond my own death, toward the death of the other man (*sic*), and does the human not consist precisely in thinking beyond its own death?" (quoted in Robbins, 2001, p126). The question stems from Levinas' disagreement with Heidegger, who placed great ontological significance on death as the temporal end of being (see Cohen, 2006). The risk here is that the individual adopts a moral position which is ostensibly self-

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[96] For relevant discussions regarding film and Levinas, see the special issue of *Film-Philosophy* edited by Cooper (2007), as well as Cooper (2006, 2009), Aaron (2007), Downing and Saxton (2009), Gibson (2001), Davis (2004), Girgus (2010); see also Keenan (1999), Cohen (2006) and Townsend (2008) on Levinas and death.

centered as there is no clear *ethical* impulse to work communally with and for others.

The major problem Levinas wrestled with was how to reconcile the absolute alterity of the Other with the self's tendencies to adopt a totalising stance. Which is to try and avoid the problem of the self comprehending and categorising the Other before making any response, such as treating an individual differently because they are labeled as "dying". Levinas thus sought to found an ethics which ensures that responsibility *for* the Other precedes the question of *how* to be responsible for the Other. Levinas positioned ethics as "first philosophy" – before being, before knowledge. Zygmunt Bauman helpfully outlines the implications of this: "Ethics looks in the 'before' of being [...] because it knows that it is *precisely the act of looking there* which founds the moral self, being as it were the only foundation morality can ever have and the only one it will ever afford" (1993, p76). Ethics, for Levinas, is the process of continually justifying why the self's infinite responsibility towards the Other was not being met. In arguing that the death of the other, not the self, was the primary responsibility of being, Levinas moved away from the comforts of ontological security and opened up an anxious and uncertain plane of ethical responsibility with no guarantees of ontological security.

The pertinence of this to the present discussion is the wish to formulate an ethical preface to spectatorship in the encounter with the dying individual: a momentary space before full submission to the spectacle where the socio-cultural (and thus ethico-political) is instated into the act of watching. In pursuing the question of the spectator's responsibility, I will consider three films which stage quite direct encounters between spectator and dying individual. In each, albeit for very different purposes, the spectator is routinely positioned as both camera and companion. Whilst Hollywood melodrama *My Life* (1993) naturalises this dynamic, *Wit* (2001) works to expose the spectator as complicit with the camera in wanting to keep dying framed and at a distance. Finally, *Lightning Over Water* (1980), where documentary and fiction collide, collude and confuse, accords the spectator no safe position from which to watch. Instead, watching itself is presented as a deeply troubled subject position, fraught with unsettling ethical questions that have no necessary solution. As such, it will be argued as an essential text for rethinking how the dying individual is encountered on screen. This argument is not simply made for intellectual and theoretical interest: there is a necessary praxis to the following discussion. *Wit* and *Lightning Over Water* are suggested as particularly useful texts for purposes of death education, in social and medical settings, because they engender an actively ethical subject position. Neither is concerned with "doing the right thing" but rather in continually questioning what "doing the right thing" even means.[97]

John Tercier (2005) argues that the act of watching death and dying on screen produces a physical response – "a *frisson*" – which marks the pleasure of transgressing social taboos. He speaks of the typical spectatorial dynamic in terms of how: "We make of the dead *things*, distancing ourselves from them, not just to achieve the emotional detachment necessary to go on living […] but so we might apprehend what we as survivors are graced with and sentenced to – life. […] In the end, we violate the dead so that we might feel alive" (pp216-17; emphasis in original). The climax to the 1993 Hollywood film *My Life* captures this dynamic

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[97] This is thus to draw on the distinction between "morality" and "ethics" made by Aaron (2007), Saxton and Downing (2009) and others. Specifically, the particular spectatorial responsibility I am advocating aims for what Aaron elucidates as the "prioritisation of (ethical) recognition, realisation, reflection – the stuff of agency – over (moral) prescription, proclamation and punishment – the stuff of ideology" (2007, p109).

well, and thus serves as a paradigmatic text for terminal illness films as a whole. The film spans the period between protagonist Bob Jones receiving a diagnosis of cancer and his ultimate death. Bob’s wife, Gail, is pregnant, prompting him to make a video record for his unborn child, consisting of life-lessons and biographical asides. Following Bob’s death, the film cuts to a close-up of a TV screen playing a video of him reading a children’s book aloud. The camera slowly zooms out, revealing Bob's infant son enjoying the story and taking comfort from the encounter [fig. 28]. Gail, sitting to one side, draws similar solace.

Fig. 28: Bob, on screen, reads his son a story in *My Life* (1993)

This scene could be considered for its mending of the patriarchal gap Bob’s death opened up, or its quasi-religious promise of life extending beyond the mortal boundaries of the body. What concerns me is a different, although not unrelated, concern. This scene, not even Bob’s death, is what the film has been building to. Within the private family context of the diegesis, the last thing Bob’s wife and child want is to only ever be encountering him in recorded form; however, it is a salve and it is all they have. The film’s spectator, however, has been cued throughout to anticipate this moment. From the opening moments of the film, Bob is seen recording himself speaking to his unborn child. These scenes are framed from the perspective of the video camera. Or rather, the film's spectator is interpellated as Bob's ideal spectator: his child. Indeed, the autobiographical stories imparted by Bob function throughout as narrative exposition.

In this final scene, therefore, the spectator gets to take a step back and is moved precisely because they have spent the past two hours routinely imagining themselves in the intimate space where the child is now sat. The spectator's entertainment is thus entangled in Bob's dying. Or, to rephrase that, the spectator's price of submission to the spectacle is their disavowal of any complicity in anticipating – and speculating on – Bob's suffering. As a dying individual, he is made into a '*thing*': an audiovisual object sacrificed for the self-centered interests of the spectator. Furthermore, whilst a wealthy middle-aged married man is an unusual protagonist, *My Life*'s narrative is little different from many other dramas of terminal decline. The spectator expects to end the film shedding and sharing tears with the dying individual's family and friends on screen.

Fran McInerney's survey of terminal illness films offers a useful expansion on this point. Whilst she mainly considers mainstream American fictional film, her conclusion is worth citing at length:

> the dying are passive players; their agency is of the sacrificial endurance kind and the narrative focus is principally on survivors. The dying journeys depicted are largely linear; traversing a 'diagnosis-to-death' trajectory in a 100–minute span leaves little time for oscillation. […] Ceding to cinematic aesthetic requirements, overt bodily disintegration is seldom depicted. […] Cinematic dying, enacting the narrative imperative for a 'happily ever after', promulgates passivity, linearity, beauty, resolution and salvation in the face of mortality (2009, p213)

Having watched the films McInerney considers,[98] I concur with her observations. There are, however, some significant limitations. The absence of non-American cinema, as well as documentary and experimental film, is problematic and will be addressed below. Also, whilst McInerney does note the preponderance of dying middle-class, white mothers, and the corresponding absence of elderly deaths, she fails to significantly explore some essential political questions, which are particular pertinent given the popularity of the texts she examines. Specifically, to draw on Judith Butler's (2004) term, there is the question of how the cinematic frame helps to construct and govern what society considers a "grievable life". That is, does film collude in wider ideological formulations by presenting the death of certain bodies and beings as more tragic, more deserving of our grief, than others, whether that be regarding age, gender, race, nationality, sexuality, disability, or so forth. (Conversely, of course, is the question of which individuals are invisible to representation.) There is not the scope to explore this further here; however the precise makeup of the dying individual in audiovisual discourse certainly warrants further study. Equally, the cause of death deserves attention: does cinema exaggerate the prevalence of certain conditions (such as brain tumors and leukemia) whilst excluding others (such as colorectal cancer, respiratory disease and, indeed, the co-morbidities of old age)? Furthermore, of course, is the question of how film might facilitate the construction of "illness as metaphor" (see Sontag, 2002).

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[98] These are: *Dark Victory* (1939), *Love Story* (1970), *Shadowlands* (1993), *Terms of Endearment* (1983), *Beaches* (1988), *Fried Green Tomatoes* (1991), *Stepmom* (1998), *Steel Magnolias* (1989), *One True Thing* (1998), *Two Weeks* (2006), *Evening* (2007), *My Life* (1993), *Life as a House* (2001), *Wit* (2001), *An Early Frost* (1985), *Longtime Companion* (1990), *Philadelphia* (1993), *The Bucket List* (2008), *The Notebook* (2004), *Iris* (2001), *Away from Her* (2006), *On Golden Pond* (1981). Alongside these, and staying within the domain of mainstream American terminal illness film, I have also watched *Unstrung Heroes* (1995), *The Mighty* (1998), *Autumn in New York* (2000), *My Life Without Me* (2003), *Henry Poole is Here* (2008) and *Things Fall Apart* (2011); as well as *Last Holiday* (2006), *The Guitar* (2008) and *50/50* (2011) which are films where a potentially "dying individual" is granted a complete cure in the closing act. See also the films cited in the notes below.

The lack of non-English language films in McInerney's survey, particularly those which have been both acclaimed and well-circulated in the Western marketplace, is a problematic absence in many respects.[99] In such films, there is often, although not always, a "narrative imperative" for tragedy-ever-after. Moreover, operating under different "aesthetic requirements" and tenets of realism, such films frequently present the body in decline much more graphically than their Hollywood counterparts (a similar distinction could be made regarding "independent" productions). Yet these representations are still wedded to spectacle. Whilst we might consider an axis of alleged actuality, between, say, Jennifer's beautified body in *Love Story* (1970) and the tangible corporeality of *The Death of Mr. Lazarescu* (2005), or between the mawkish melodrama of *Stepmom* (1998) and the inexorable stasis of *La Gueule ouverte* (1974), these films have all been carefully constructed to achieve their desired ends. Furthermore, all offer the spectator the comforting container of narrative and the security that any performance of dying is only ever just pretend. Such displacement sustains distance: the messy everyday of actuality is smoothed over through submitting to the appealing sheen of spectacle. Given this, how can we formulate the spectator's responsibility in such an encounter?

Michele Aaron (2007) proposes an ethics of spectatorship based upon its inherently intersubjective nature. That is, the spectator's "pleasure" – that which is gained from the act of watching – is based upon their "intersubjective alignment with the suffering of others" (p112). However, the implications of that are excused through an implicit contract. The spectator accepts illusion as reality through the assistance

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[99] For example, *Ikiru* (1952), *Cries and Whispers* (1972), *La Gueule ouverte* (1974), *The Barbarian Invasions* (2003), *Le temps qui reste* (2005), *The Death of Mr. Lazarescu* (2005) and *Biutiful* (2010).

of the Spectacle: “I'll forget that you're fake, as long as you help” (2007, p91). This act of forgetting – this disavowal – “allows one to indulge in fantasy without suffering the consequences of it” (p92). However, it is precisely at the point of this disavowal in which the spectator becomes complicit. That is, with cinema so occupied with stories of suffering, disavowal is the defence mechanism that ensures they are encountered at a safe distance. Consequently, these stories of suffering can be selected, watched and walked away from, without any introspective questioning of intent. An ethical rethinking of the encounter between spectator and Bob in *My Life* thus stresses its fundamental intersubjectivity. In so doing, the spectator’s straightforward disavowal of complicity becomes untenable. The spectator therefore becomes responsible for their response. Accordingly, the ethical space is that which comes before such responsibility is shirked in favour of submission to the Spectacle.

Aaron (2007) suggests the relevance of Emmanuel Levinas to any formulation of an ethics of spectatorship and the “response-ability” of the spectator.[100] For Levinas, it is the “face-to-face” encounter between self and Other which forms the ethical foundation for all that follows. In the encounter, the self is constituted in a boundless and unconditional responsibility for the ungraspable and unknowable Other. The self owes the Other everything (for Levinas this is quite literal). The self’s responsibility is also infinite. It cannot be quantified, or dealt with, or put aside. It is also asymmetrical: the self cannot expect reciprocation. The self must justify their presence in the world – literally the fact that their existence takes food, water, oxygen from others – through recognising, reflecting on and responding to the demands of the Other.

The inference of Aaron’s (2007, pp110-113), and others, use of Levinas in

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[100] See also especially Saxton and Downing (2010), Gerbaz (2008), Cooper (2006, 2007) amongst others.

relation to spectatorship is that the suffering individual on screen is analogous to the Other in the face-to-face encounter.[101] However, the "face-to-face" encounter is not as straightforward as it appears. For Levinas, the face of the Other is explicitly not a physical face. Indeed, it is not perceivable. Rather, Levinas is speaking of a presence that is "incomprehensible" and "overflowing" (1969, p195). As such, the face-to-face encounter is not an empirical encounter. Accordingly, as Levinas puts it: "if you conceive of the face as the object of a photographer, of course, you are dealing with an object like any other object" (quoted in Robbins, 2001, p48).[102]

Seeking to escape such an impasse to theorising the spectator as one half of the face-to-face encounter, Alex Gerbaz asks, "surely the moving images of cinema constitute an exception?" (2008, p21). He suggests that certain texts may enable the spectator to "orient oneself before the face in such a way as to 'see' or think beyond its form" (p22). Similarly, Libby Saxton (2007), following Judith Butler (2004), suggests that the revelation of the "face" in representation is possible, "precisely to the extent that it fails to represent it and – crucially – acknowledges this failure" (p11). I follow Gerbaz and Saxton to a point, as will be seen in my discussion of *Wit* (2001) below, but I find it difficult to reconcile Levinas's account of the ethical encounter, with their application of it to film. However, absent from both of their formulations is the other party to the Levinasian encounter: the Third. Through reinstating the Third's presence, a new way to view the spectator's place in the face-to-face encounter emerges.

For Levinas, the encounter between self and Other always occurs in the presence of the Third. If it was just an encounter between self and Other, there would be no justification for the self not to give themselves completely to the Other. However, as

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[101] This is also true of Gibson (2001), Davis (2004), Knox (2006), Gerbaz (2008) and others.

[102] Levinas held a particular distrust of representation, discussed in his writing but also echoed in his struggles with language (see Hand, 2009, pp63-79).

Levinas puts it: “Because there are more than two people in the world, we invariably pass from the ethical perspective of alterity to the ontological perspective of totality” (cited in Cohen, 1986, p21). By this he is referring to the Third, which can crudely be understood as society, but more specifically refers to the countless other Others, each with their own infinite demands. Whereas the Other had been unknowable, now they can be identified and categorised. As Bauman suggests, with the arrival of the Third, “the site is cleared for norms, laws, [...] rules and courts of justice” (1993, p114). It also brings codes of moral conduct, offering the self relief from their infinite responsibility towards the Other by providing external guidance on how to act. The ethical consists of the process through which the self challenges – rather than accepts – such moral frameworks. Accordingly, the ethical can be understood as the need for the self to respond to the Other not by following a socially approved code of conduct and “doing the right thing”, but through the introspective interrogation and reflective questioning of what that even means. The price for this is uncertainty. However, it is in embracing, not disavowing, this uncertainty that the ethical stance is founded (Bauman, 1993, p221). Furthermore, in challenging existing orders, this process has a social impact. As William Simmons elucidates, “a resuscitation of the ethical is needed to check the political” (1999, p92).

Returning to spectatorship, having included the Third in the encounter, resolves the need to locate the face of the Other within the filmic frame. Indeed, instead, the Other can be seen as entirely outside any frames of representation and – more importantly – fields of representability. The ethical can be regarded as the spectator thinking about the Other outside such structures, whilst recognising – and questioning – the moral frameworks shaping their encounter with the film-world on screen. Whilst submission to the Spectacle is wedded to self-interest and pleasure, this ethical position is anxious and uncertain. One way to conceive this is that prickly feeling of unease sometimes felt when watching a film with somebody you sense is uncomfortable with its content. You are forced to read the screen differently, partly, perhaps, through their eyes. You possibly find yourself hoping that nothing will be said, the moment will pass, and you can get back to enjoying the film. The process, however, raises questions about your pleasure – and another's discomfort – in submitting to the Spectacle. Accordingly, put very crudely, the Third can be thought of as the Spectacle, whilst the Other is the unseen other sat by the spectator's side. The ethical preface to spectatorship is therefore the moment of unsettled accountability, where the spectator justifies their submission to the Spectacle to the unseen and unknown Other. I turn now to two films which work to instate the ethical into the act of watching. *Wit* (2001) and *Lightning Over Water* (1980) both encourage the spectator to question and challenge how the dying individual is normally encountered on screen.

As we have seen, the dying individual is typically screened for the benefit of the spectator. Moreover, the dying individual is routinely objectified and constructed as separate from the living. It is precisely this which the film *Wit* (2001) works to unpick. *Wit* is a 2001 television adaptation of a Pulitzer Prize winning play.[103] Emma Thompson plays Vivian Bearing, a professor of English literature, who is dying of ovarian cancer. The film's narrative – diagnosis, decline and death –

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[103] For a relevant discussion of the film and ethics, see Knox (2006). For a relatively contemporaneous anthropological study of end of life care in American hospitals see Kaufman (2005). The play (Edson, 1999) and the film, have been used as a tool for training American medical students to try and improve patient care. *The Wit Film Project* (previously *The Wit Project*) was created for precisely this purpose. More information can be found at the project website: http://www.growthhouse.org/witfilmproject/index.html [Accessed September 28th, 2012].

mirrors many a melodrama. What differs here, however, is Vivian's solitude. The film opens with a set of jagged, jarring chords on the soundtrack, followed by an imposing extreme close-up of a doctor announcing "you have cancer". That is, diagnosis occurs before Vivian is even seen. The doctor is standing, looking down at Vivian. In the reverse-shot that reveals her, taken from his point-of-view, Vivian looks directly into the camera. From the outset, then, the spectator is aligned with the clinical position. This shot, where Vivian's look unsettles the diegetic boundaries of the frame, establishes a prising apart that occurs throughout the film.

This prising apart becomes much more explicit in the scenes that follow. Vivian enters hospital for treatment and begins narrating her story to the audience. Across the flashbacks of the film's first half, Vivian seems to be literally steering the chronological presentation of events.[104] She interacts both directly with the spectator and within the diegesis. This all conveys the impression, so to speak, that Vivian is framing herself. Her experience – the content of her narrative – is of having her subjectivity ignored through her reduced status as patient. She has become a body to be done to, not a person to be engaged with (let alone responsible for). Vivian has no family and no visitors. The spectator is thus interpellated, through Vivian's direct address, as her only companion, separate from the totalising clinical and institutional confines.

These confines are initially the stuff of content, but they soon take on the tenor of form. As she begins to weaken physically, Vivian's narrative agency diminishes. That is, she increasingly becomes the subject – or rather object – of the narration. This is first figured mid-way following a fade-to-black. The soundtrack reprises the jagged chords from the opening and the black screen cuts to a very sick Vivian

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[104] The play is more explicit about this. It opens with Vivian addressing the audience (with lines that appear in scene 2 of the film) and introducing the play as a play (i.e., "I've got less than two hours. Then: curtain." (Edson, 1999, p7).

being readmitted to hospital. The scene that follows bears no indication of Vivian's narratorial control – not even a look to camera. Whilst her direct address subsequently returns, the film now follows a linear progression towards Vivian's death. Where before Vivian's mental recollections were shared with the spectator, introduced with lines like “I can recall ...”, now the film simply intrudes on them. This intrusion is dramatised when a nurse, who has arrived to take Vivian away for a test, appears within the once safe space of her mind’s-eye. With this, comes an increase in Vivian's allusions to the artifice of dramatic representation. Earlier, for example, she observes how the film is only showing the “interesting” moments of her hospital stay and not adequately conveying the tedium she experiences. She remarks: “If I were writing this scene it would last a full fifteen minutes. I would lie here and you would sit there”.

This revelation of artifice reaches a crux in a scene where she is left alone, awaiting an ultrasound, and begins to address the audience. The camera slowly approaches Vivian until she is framed in tight close-up [fig. 29]. She says: “My next line is supposed to be something like this: Oh, it is such a relief to get back to my room after those infernal tests’. This is hardly true. It would be a relief to be a cheerleader on her way to Daytona Beach for spring break. To get back to my room after those infernal tests is just the next thing that happens”.

Fig. 29: Vivian addresses the spectator in *Wit* (2001)

The film then suddenly cuts to Vivian, falling back into her hospital bed, giving a deliberately exaggerated line reading: “Oh God, it is such a relief to get back to my goddamn room after those goddamn tests”. This produces a fracturing of the spectatorial contract which is never fully mended. Whereas before the spectator was welcomed as companion to Vivian’s dying, here they are left bereft of any certainty that such a welcome was genuine or scripted. Or rather, the spectator’s responsibility becomes about much more than mere presence in the encounter. It becomes instead about accountability for spectatorial demands, which have become explicitly linked with dehumanising medical discourse and, more subtly, aligned with the spectator’s need for Vivian’s dying in order to provide them with a narrative to watch. This specific revelation of Vivian's subordination to narration – and thus to the spectator – is the culmination of the prior thematic and formal prising apart. What results is a distrust of narration – which nevertheless is all there is. However, the spectator's price of submission – complicity in Vivian’s subordination to object status – has been exposed.

I am arguing, then, that *Wit* works to unsettle the cinematic frame which always already contains the dying individual, objectifying them through the camera’s totalising lens. That is, it both exposes *and* traffics in the production of dramatic interest and acts of narrative containment which stage the fictional encounter for the benefit of the spectator. Moreover, it seeks to reveal the formal fabric of disavowal, through which the spectator typically submits to the cinematic spectacle. We thus have in *Wit* an encounter concerned explicitly with the violence representation – as characterization and narration – does to the dying individual, which is furthermore concerned with revealing the same effect of institutionalisation and medicalisation. The spectator is seated in a position of complicity, whose only recourse is a reconsideration of that role. Or rather, the spectator's responsibility is awakened in a perpetual reflection on their reduction of Vivian to an object of perception, a reduction that has been explicitly linked with dehumanizing medical discourse. In so doing, concern shifts to the construction of Vivian's – fictional – dying, which has been witnessed, rather than simply watched and walked away from.

Accordingly, *Wit* provokes the questions of spectatorial *responsibility* raised at the start of this chapter. It refuses to let the spectator rest as both camera and companion. Rather, the violence of the former is revealed and left exposed, a revelation that the spectator must either disavow or somehow accommodate (and justify). As such, *Wit* not only muddies the sheen of the Spectacle, it undermines the pretence that the dying individual can be encountered on-screen without the spectator ceding certain ethical responsibilities. *Wit*, however, sets out to do this; it is structured to give a strong inkling as to what the right response is. *Lightning Over Water*, on the other hand, flat out refuses.

Before turning to *Lightning Over Water*, the final limitation of McInerney's survey of terminal illness films needs addressing: the absence of documentary.[105] Whilst films which take actuality as source material are clearly distinguished from their fictional counterparts, when considered in relation to how they screen the dying individual, certain similarities remain. Namely, the fundamental spectatorial dynamic in documentary is no different to its fictive equivalent: the dying individual is mediated, framed and screened for the benefit of the spectator. Indeed, in many respects, documentary, whilst introducing reality into the equation, simply accentuates, rather than undoes, the pretense of actuality which the spectator clings to.

Vivian Sobchack notes the morally charged nature of documentaries which offer a direct gaze upon real dying.[106] She observes too how few documentary representations there are of natural death. For Sobchack this is partly because:

> gradual, natural death allows time and space for the ill-mannered stare to develop and objectify the dying. The filmmaker's ethical relation to the event of death, the function of his or her look, is open to slow scrutiny by

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[105] Such as, *Near Death* (1989), *Silverlake Life: The View from Here* (1993*), Sick: The Life and Times of Bob Flanagan, Sadomasochist* (1997), *Dying at Grace* (2003) and *How to Die in Oregon* (2011). Within this category are also more experimental works which draw upon documentary, such as Bill Viola's *The Passing* (1992) which incorporates footage of his dying mother.

Interestingly, *Lightning Over Water* isn't the only recorded encounter between film directors where one of whom is dying. See also Chris Marker's film of Andrei Tarkovsky, *One Day in the Life of Andrei Arsenevich* (1999) and Agnes Varda's film about her husband Jacques Demy, *Jacquot de Nantes* (1991). A related film is *Letter from a Cherry Blossom* (2003), where director Naomi Kawase films the last days of Kazou Nishii, a Japanese photographer and film critic. Similarly, both Jonas Mekas's record of Allan Ginsberg's dying, *Scenes from Allen's Last Three Days on Earth as a Spirit* (1997), and Paul David's *Timothy Leary's Dead* (1996), document and present the final days and weeks of two major cultural figures.

[106] Sobchack actually uses the term "ethically charged" (p248). Bill Nichols expanded Sobchack's thoughts, seeking to develop a broader understanding of ethics in documentary, which he termed "axiographics". Nichols is concerned with asking "how values, particularly an ethics of representation, comes to be known and experienced in relation to space" (1991, p77). As Lisa Downing and Libby Saxton argue, both Sobchack and Nichols "used the term 'ethics' in a general sense which remains bound up with traditional ideas of moral judgment" (2009, p12). Therefore, whilst I follow their acute analysis of ideology, I consider it an interrogation of the formal fabric of *morality*, rather than the ethical.

> the spectator. [...] The viewer (both as filmmaker and spectator) bears particular subjective responsibility for the action marked by – and in – his or her vision. (2004, pp242-43, 248)

Therefore it is essential that the viewer's gaze on real dying is structured as welcomed and invited (p254). Although there are clearly differences between documentary and fictional figurations of dying, I suggest that they both function similarly. Whilst documentary amplifies the “subjective responsibility” of the spectator, both it and fiction are typically concerned with mitigating or disavowing what that responsibility entails. For Sobchack, “as the filmmaker watches the dying, we watch the filmmaker watching and judge the nature and quality of his or her interest” (p243). What gets disavowed is the spectator’s responsibility for “the nature and quality” of *their own* interest. This is basically to agree with Aaron (2007) that real and fictional representations of suffering can be placed “at either ends, of some kind of continuum of spectatorship”. The spectator to both is engaged in an act where he or she is “looking on” at the suffering of another, which surely raises “questions of personal and social response and responsibility” (p122). That is, the dying individual, in both documentary and fiction, is framed in a manner which keeps those spectatorial questions of responsibility at bay. Questions which would otherwise address the *social* positioning and *ethical* entanglements of the spectator are rejected in preference of self-interest.

The director Maurice Pialat, whose own *La Gueule ouverte* (1974) is a raw and challenging story of dying, was once asked if there was any subject he would never film. He replied: “*Lightning Over Water*” (*Cahiers du cinema*, 1981). *Lightning Over Water* began as a collaboration between directors Wim Wenders and Nicholas Ray, who was dying of cancer. The initial, fictional, idea was scrapped due to Ray’s ill health. Instead, the two improvised scenes where they played themselves, performing the very roles they were actually in: Wenders, a director, arrived to make a movie with Ray before his death. Tom Farrell, Ray's assistant, constantly shot video footage of the proceedings. Ray's condition worsened and shooting was abandoned. Wenders filmed some more footage before abandoning the material to his editor. The result, titled *Nick's Movie: Lightning Over Water*, played at Cannes in 1980, however Wenders was not happy with the result.[107] He felt it told a story in the "third person" which should have been in the "first person". He spent three months re-editing it, adding a voice-over and giving it a stronger chronological and linear narrative. His – definitive – version, now simply *Lightning Over Water*, was released in 1981.[108]

The finished film charts Wenders's arrival at Ray's apartment, the difficulties they faced in making a film, the declining state of Ray's health and finally a wake, on board a boat, held by Wenders and his crew. Jon Jost, in a scathing article (based on the original cut), accuses Wenders of refusing Ray "love", and instead "[seeming] to perceive life only through the mechanical devices of film." He goes further: "They rolled [Ray] over with a movie-making machine and now they even

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[107] That version, according to Kathe Geist, was characterised by "[e]xtreme disjunctive editing and longer speeches, which tended toward obscurity" giving it "a highly personal, ultimately morbid quality" (1981-1982, p48). Ivone Marguilies also notes that it "avoids the linearity that would signal a fictional construction" (1993, p55).

Confusingly, some of the commentary on *Lightning Over Water* fails to distinguish which version is being described. In a commentary for a DVD release of the film, Wenders (2003) claims that only one print of the original exists, in an archive in Germany. Mistakenly, in 1987, the original version was released on video in America (which Kolker and Beicken (1993, p91) ironically consider to be a third edit). Scheibler's (1993) reading, discussing the "performative" aspect of the film, appears to be based upon this video. Scheibler refers to a scene between Wenders and Susan Ray (p147) which isn't in Wenders' final cut. She also doesn't mention the voice-over that distinguishes the two versions.

[108] Unfortunately, in the following, limitations of space prevent me doing justice to the complexities of *Lightning Over Water*. There has, however, been much fascinating work done on the film concerning questions of performance, narrative and death. See especially, Burnett (1981), Chamberlin (2005), Corrigan (1985), Geist (1981-1982), Jost (1981), Margulies (1993), Russell (1995, pp67-104), Scheibler (1993) and Naremore (1988, pp19-21). See also Ray's wife Susan's discussion of and problems with – the project (Ray, 1995).

choose to display the carnage" (1981, p96)[7]. This attack hides a personal bias (Jost wanted to make a final film with Ray), but it usefully articulates the particular fear that haunts Wenders – an anxiety which is expressed literally and structurally throughout the film. Indeed, Wenders's "first-person" reworking forces the spectator to share his "subjective responsibility", that is, to share his anxiety. However, Wenders's on-screen, and slightly uncomfortable, performance as himself, also places him as the main protagonist. In Metzian terms, he is the site of the spectator's primary and secondary identification (see Metz, 1977).

Wenders renders his anxieties visually in a dream sequence midway through the film. In voiceover, he comments on how the cinematic apparatus, and the daily logistics it demanded, consumed his time, "rather than being concerned with Nick". Even in sleep, Wenders says, "the camera would always be there". This is followed by shots of Ray superimposed onto the camera on the deck of the boat carrying Ray's ashes [fig. 30].

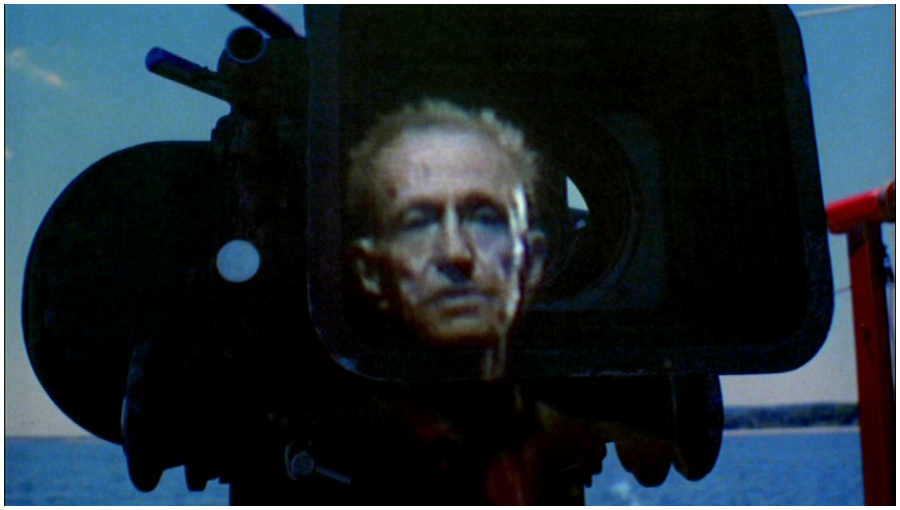

Fig. 30: Wim Wenders's nightmare in *Lightning Over Water* (1980) sees Nicholas Ray superimposed on a camera.

The film thus stages the encounter between spectator and Ray wholly within the framing imposed by Wenders. The film's indexical instability is further troubled by its temporal doublings. The performative nature of the footage is undercut by the past-tense of Wenders's voice-over. Furthermore, the ugly, draining palette of the video-footage contrasts troublingly with the bright, clean sheen of the film. The film therefore refuses a stable viewing position. The only stability in the encounter is the fact that it is always mediated, ever shifting. However, this banality, accentuated by the ongoing moral anxieties expressed by Wenders, constantly unsettles the frame. In doing so, it ruptures the shared contract of subjective responsibility between spectator and filmmaker, and creates the conditions for a new one – between spectator and Ray – to emerge. In this new contract, the watching conditions are remarkably different. Spectatorship here becomes a performative act, posthumously producing Ray's existence against that which seeks to contain it. Equally, this opens the film up to Ray's creative contribution.[109]

Ray and Wenders together scripted and improvised, with Ray directing Wenders, in all the scenes in which they appear together (with the exception of the scene when Ray is in hospital). Ray's performance as/of a dying man challenges the conditioned cultural response to look away. A viewer is required, for without a witness the action is worthless; but that viewer must be actively constructing Ray's presence – bringing him to life as an unknowable individual. Ray's last, loosely scripted scene, sees him almost incoherent, addressing Wenders and his cancer, saying: "you're making me sick to my stomach". Wenders, off-screen, tells him to

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[109] Although Wenders generally gets credited for the experimentation, it should be remembered that Ray's work was becoming increasingly radical in both form and production. His unfinished final film, *We Can't Go Home Again* is testament to this. Carloss Chamberlin (2005), in one of the few critical readings emphasising Ray's creative role, sees it in these terms: "[t]he plot of the film is the story of an actor (Ray) controlling the director (Wenders) through the brilliant use of his weakness. Wenders' benign sadism, the sadism of all directors who have to get the shot, is his performance."

say "cut", which he does, several times, but the filming continues and Wenders replies "don't cut". Finally, forcefully, speaking directly into the lens, for one last time, Ray says "cut" and the screen goes black. This scene is cued, diegetically, as being Wenders's dream, so though charged and heavy with meaning, contextually it places Ray's final performance – death – as something he will never perform on camera because the physical and socially permissible limit of performance has been reached.[110]

Fig. 31: Wenders watching Ray in *Lightning Over Water* (1980)

The spectator and Wenders find a point of contact in Ray's creative agency: the film is replete with moments of Wenders watching Ray's work, in film, as a theatre director and as an actor [fig. 31]. The spectator becomes a guarantor that Ray achieves the restoration of "self-image" he sought. However, there is no guarantee that this is the "right" response and, particularly in the video-footage of Ray, that watching is at all welcome (and *vice versa*). This constant negotiation of response and the continual cycling between performance, actuality and potential exploitation, begins to reveal the formal fabric of spectatorial disavowal. That is, it brings to the fore the usual means of filmic relief – the defacement of the dying individual – and reveals the ethical price that comes at. The spectator, in becoming more concerned

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[110] As a marker of the film's indexical instability, both Kolker and Beicken (1993, p91) and Russell (1995, pp78-79) mistakenly place this scene as actually taking place in hospital, with the former viewing the improvised dialogue as being straight documentary.

with Ray than in shoring up their “ontological security”, rubs against the grain of the frame and suggests another way of watching.

I want to conclude by returning to *Death Watch*. Late in the film, Roddy confronts the consequence of his dual role as camera and companion. Entering a pub, he sees a television which is screening Katherine in the show ‘Death Watch’. We share Roddy’s perspective as he re-experiences a private encounter he recently had with her, now being broadcast for the entertainment of millions [fig. 32]. Seeing this triggers a breakdown. Roddy blinds himself (destroying the camera) and reveals the truth to Katherine. Together, as true companions, they try to evade the gaze of the production company. In the television executives’ most cynical revelation, we discover that Katherine, initially, was never dying. The diagnosis of terminal illness was a lie, intended simply as a stunt to provide ratings. However, the drugs she was prescribed as part of the pretence are, in fact, slowly killing her. Ultimately, Katherine takes her own life.

Fig. 32: From *Death Watch* (1980)

This is, perhaps, a despairingly cynical note on which to end, suggesting that the only escape from the Spectacle involves the ultimate severing of spectatorship: to stop watching; and that the only hope for the dying individual to achieve agency from the self-interest of the spectator watching them is through suicide. But such ruins offer the opportunity for the spectatorial contract to be rebuilt: for the spectator, at a minimum, to recognise that the dying individual is being screened for their benefit and that such self-interest does real-world violence. This – precisely this – is the foundation for an ethics of spectatorship in the encounter between spectator and dying individual. Such an awakening of ethical responsibility cannot bear the burden of further dictates: it is not about the spectator being instructed on what the moral thing to do is, but rather perpetually thinking through what doing the right thing even means. As such, as a starting point, *Wit* and *Lightning Over Water* offer themselves as vital texts in the service of death education, for a multitude of social, medical and political purposes. The hope, through such, is that there can be a restructuring of the *status quo*, so that the dying individual will cease to suffer the inequities and inequalities of stigmatisation, isolation and abandonment so as to appease the death anxiety and shore up the ontological security of the so-called "living".

CONCLUSION

I conclude by returning to my opening remarks: We are all dying individuals. Our existence is fragile and finite. Death or a terminal disease can come at any moment. Right now, you, or someone you love, might have a cancer, or a lung condition, or a blood-borne virus. I say that not rhetorically, but as a reality. To say that we are all dying individuals is simply to admit that our time is limited, our end guaranteed. It is also to challenge – on political and ethical grounds – the social and cultural *status quo* which insists that dying is opposite to living, rather than a process within it.

The "perceptual world of the living" presently sustains the *status quo*, ensuring that the encounter with the dying individual is always already foreclosed. In the twentieth century, Western society strove to create order out of dying. Death represented an insurmountable challenge to modernity's attempts to master and manage everyday life. It also undermined dominant ideologies that advocated individualism and consumerism over communal interdependence. In the process, society subjected the dying individual to an existence which took scant account of their presence as anything more than an object in the universe. Dying had once been a familiar – if tragic – occurrence, with family, friends, neighbours and sometimes strangers ensuring constant companionship to those who were dying. However, the medicalisation and institutionalisation of death resulted in the isolation, stigmatisation and abandonment of the dying individual. The subsequent severing of community and communication become a naturalised state of affairs.

Visual culture exacerbated, rather than challenged, the absence of the actualities and banalities of dying. Death, where publically seen, is mostly violent and spectacular, typically separated entirely from the realities of everyday life. When the dying individual is encountered, he or she is typically figured for the benefit of the spectator. The spectator is given certain securities that death can be meaningful and contained within a framework. This helps placate their death anxiety and shore up their ontological security. The "perceptual world of the living" thus regulates the presence of the dying individual, to ensure that their lived experience is framed in a manner that maximises anybody's capacity to disregard it.

Many are seeking to change this. Alongside institutional changes to end of life care, there are efforts being made to challenge the barriers of taboo which inhibit necessary dialogue and exchange. The broad aim of such reforms is to return the dying individual to the communal fold where they can hopefully enjoy a "good death". Visual culture is being used as a means of achieving this, from holding public exhibitions to producing films for wide distribution. The accessibility and immediacy of such texts has rightly been viewed as a way to both raise essential questions and ultimately try to instigate real world changes. However, there is a problem, or rather a risk, with such approaches. The visual currently contributes to the present devaluation of the dying individual, whether through objectification or occluding their subjective presence. To effect real change, the structures of otherness that govern the "perceptual world of the living" need to be identified and unsettled. As a consequence, this requires a willingness to challenge individual complicity in submitting to structures which perpetuate the *status quo*.

But what does this mean in practice? Simply, there is a need to address the fact that mainstream visual culture typically presents dying as shocking – like the images of Barb Tarbox, Gary Coleman and David Kirby seen in the introduction – or, alternatively, proffers fantasies of the "good death" – such as the mainstream films considered in chapter four. Such texts work to entrench a false division between "living" and "dying". This is precisely the divide that the "perceptual world of the living" sustains through governing representability. It is thus not enough for reforms to seek to accommodate the dying individual within the perceptual world of the living: in order for them to return as equals, the structures that currently construct them as different need to be identified and exposed for the damage they do. This means stripping some of the securities that are currently accorded to appease the spectator's death anxiety. Equally, idealised notions of the "good death" – which stem in part from public unfamiliarity with dying – are counterproductive. Instead, there is a need for a public restoration of the dying individual's lived experience in a manner which does not objectify or demean them.

Such a process necessitates fostering solidarity between spectator and dying individual. This is in contrast to encouraging compassion *towards* the dying individual, the dominant approach in end of life care reforms. Moreover, though, whilst such reforms helped set these problems out, fostering solidarity can be seen as central to an ethics of spectatorship. The documentary photography considered in chapter three showed how solidarity stems from the spectator rejecting a stance of mastery and accepting that such a subject position makes them complicit with structures of otherness that carve artificial distinctions between individuals. With the spectator and dying individual as equal citizens in the civil contract of photography, images become a site where fields of representability can be revealed and challenged. In film, solidarity is still possible, but harder to sustain. Mainstream narratives of dying typically serve the self-interest of the spectator, who seeks to disavow their complicity in being entertained by somebody else's suffering. However, texts like *Wit* (2001) and *Lightning Over Water* (1980), open up opportunities for ethical reflection, where the spectator is forced to question how the dying individual is encountered – and framed – on screen. In doing so, they rub up against the grain of the frame and reveal different viewing relations based upon companionship rather than mastery.

At the start of this thesis I asked: Is it possible to unsettle the structures of otherness governing the perceptual world of the living, or must the encounter with the dying individual be always already foreclosed? Whilst the answer is a frustrating yes to both, once this is accepted, new possibilities emerge. The spectator's responsibility stems from recognising the totalising potential inherent in their subject position. This can then facilitate the unsettling of frames that seek to construct the dying individual as different from the "living". Such an ethics of spectatorship works to recognise frames which purport to contain and explain others. The dying individual cannot be bracketed in such a fashion. Where social and cultural discourse makes claims that suggest otherwise, it is the responsibility of the spectator to recognize, unsettle and reject them. By insisting on an ethical preface to spectatorship, political change becomes possible.

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