SECTION II
THE VOICES OF THE DYING PEOPLE

6. PERFORMATIVE DOCUMENTARIES

Life-Affirming Stories about Mortality

In the recesses of La Monnaie, the national opera house in Brussels, an old man peeks into a storage room. From behind a wall of plants, a dancer dressed in a skeleton suit steps into the frame. A chase ensues, the skeleton running away from the old man. Finally, the man drags the skeleton out in the open by its feet. The old man gently caresses the skeleton's face and removes the hood (Figure 6.1). The skeleton returns the touch, and they join hands, eyes fixed on one another. Slowly, the old man takes off his jacket and hangs it on a dummy. One piece after another, they remove their clothing and redress the old man to be a skeleton. They touch each other until the metamorphosis is complete, and the old man walks out of the frame as a skeleton, inviting the dancer to follow.

This scene is from Jorge León's film *Before We Go* (2014), where three terminally ill people meet with choreographers, actors and musicians to co-create artistic expressions about mortality. León describes the film as an artistic process. Patients from a hospice in Brussels and local artists were committed to the project and became as much creators as the filmmaker. While the filming at the opera house took two weeks, the work had started much earlier through workshops, researching the topic of death together, and planning and rehearsing the scenes up until saturation point. This skeleton scene, León says, was carefully outlined and prepared, but proved difficult to capture and took plenty of takes (León 2020). The atmospheric, lyrical and symbolic result suggests that acknowledging death allows an intimate, even a loving relationship with it. The scene also displays quiet humour: small smiles play on the old

Figure 6.1 Noël faces a skeleton in *Before We Go* (León 2014).

man's face when he chases the skeleton, and the skeleton costume imitates popular Mexican Day of the Dead outfits. These elements further reduce death anxiety, for they appear as Bakhtian carnivalesque (Bakhtin 1984), subverting and turning upside down the assumed social norms (death as an anxious and sombre event) through humour. Consequently, in this intimate encounter, death becomes an approachable and a non-threatening character.

Before We Go, with its rehearsed scenes with real people, is a performative end-of-life documentary. Performative documentaries use stylistic and unconventional practices where the subjects and filmmakers not only acknowledge the presence of the camera, but act out for the viewer (Nichols 2017, 151; Bruzzi 2010, 185). According to Stella Bruzzi (2010, 185, 187), performative documentaries feature the subjects' stylised performances or the filmmaker's emphasised presence. I will discuss the filmmaker's role and the performative first-person narratives in Chapter 10, while in this chapter, my focus is on documentaries which narrate the experiences of dying people through creative art. In addition to *Before We Go*, I will discuss the Swiss documentary *Bouton* (Balzli 2011) of a terminally ill ventriloquist giving voice to her emotions with the help of a puppet, and a Scottish documentary, *Seven Songs for a Long Life* (Hardie 2015), where six hospice patients choose and perform their 'final songs' to describe their feelings about their lived lives and their approaching deaths. These documentaries employ planned performances to tell unique and arresting narratives, mixing rehearsed moments with more typical documentary events, such as spontaneous attempts to show the way out to a pigeon that accidentally enters the workshop room at the opera house.

In end-of-life documentaries, act-out performances are more than alternative documentary modes: creating art is a widely recognised form of therapy in hospice and palliative care, aimed to alleviate anxiety and existential fears at the end of life (Pratt and Wood 2015; Safrai 2013). Art therapy practices play a supportive role in performative documentaries as well. León (2020) acknowledges that the starting point for the workshops between the patients and the artists lay in the long traditions in art therapy at the hospice in Brussels. Amy Hardie (2016, 257–9), director of *Seven Songs for a Long Life*, was an artist in residence at a Scottish hospice where she helped the patients to create short films about their lives, and slowly these encounters turned into a full documentary. However, rather than being representations of art therapy as a practice, the art-based performances in performative documentaries are public explorations of the dying subjects' inner emotions. León (2020), for example, emphasises that *Before We Go* is not a story about art therapy, but an experience – for the subjects and for the viewer. Performative end-of-life documentaries thus foreground the experiences and voices of the dying. In this chapter, I analyse the ethical aspects that performativity adds to the documentary experience.

Performativity and Ethical Experience

In performative documentaries, the filmed subjects become actors. They consciously create the content and roles or characters, much like in *Before We Go*. Jorge León (2020) argues that the dying people, who the viewer can recognise as actual persons as opposed to being hired actors, build their characters for staged moments. It is this combination that erases boundaries between documentary and fiction. Documentary films' history of observation, *cinéma vérité* and direct cinema have prioritised witnessing of the events with minimal influence on the scenes by the filmmaker. Consequently, documentary filmmaking and its emphasis on acting for the camera appears as an alternative approach.

J. L. Austin's speech act theory has provided a way to understanding what performativity has to offer for documentary filmmaking. In Austin's theory, words and sentences are not only descriptive, but various utterances, such as 'I now pronounce you husband and wife', also act in their own right, and as such they perform (Austin 1975). Edward Lamberti (2019, 19) adds that similarly to words, images and film have performative power, particularly when words fail to communicate the experiences. Often, our relationship with mortality can be more an embodied feeling than a conceptualised understanding. Following the embodied and affective experiences of others might therefore show us a way of reflecting our own attitudes and feelings about end of life.

Rehearsed and performed elements blurring the boundaries of documentary expression have also raised ethical questions of inauthenticity and

trustworthiness. For example, according to Bill Nichols (2017, 149–50), performative moments that turn the viewer's attention to style and (emotional) experiences distance the filmmaker and the viewer from realist representation and the film's attempt to say something authentic about the topic. From another perspective, Calvin Pryluck (2005, 200) argues that staged performances may be more ethical than actuality filming because they are signs of self-expression instead of the filmmaker's interpretations of events. I agree with Bruzzi's (2010) argument that no documentary can live up to the intention of representation of 'real', because both 'reality' and 'authenticity' are constructed in the filmmaking. Because performative documentaries include their subjects in creative processes of storytelling and openly admit that their representations are fluidly produced through filmmaking, the purposefully created scenes can thus become a source of, not a threat to, the documentary's ethical potential (Bruzzi 2010, 6–8; Hongisto 2018). Rehearsed scenes create transparency to filmmaking, while the acknowledged presence of the camera (and the viewer) demonstrates the filmed subjects' consent to being filmed.

Rehearsed performances do not invalidate documentary representations, so the question is how we understand authenticity. At its best, says Nichols (2017, 149–50), authenticity translates into spontaneous events that take place in front of the camera. However, based on Gilles Deleuze's application of Austin's speech act theory, Ilona Hongisto notes that when filmed subjects act for the camera, they are making fiction, yet they are not fictional. This turns filming into a 'creative story-telling act that has an immediate impact on the lives of the filmed subject' (Hongisto 2018, 192). These impacts are authentic and lived experiences. León saw this process take place in the filming of *Before We Go*. He realised that he was creating realities and encounters that the terminally ill would not otherwise meet in their daily lives. The staged encounters nevertheless produced experiences that had presence and meaning (León 2020). Staging turned to co-creating experiences that affected the lives of the participants – and also the viewer. Performances such as the old man's encounter with the skeleton dancer communicate unarticulated emotions related to facing death, and make claims about various, even alternative, ways of encountering it. Similarly to Bruzzi (2010, 185), who claims that performativity offers an opening for the viewer to experience what is represented, I argue that it does not erase authenticity but offers another understanding of authenticity, one where performativity emphasises the authenticity of experiences.

In other words, performative films do not seek authenticity or trustworthiness in spontaneity of events or factual knowledge, but in the desire to understand emotional, embodied and personal experiences that often lie beyond linguistic expressions or conceptualisation. León calls this 'experiential knowledge'. He argues that a terminally ill person's understanding of life and death

differs from that of a healthy person. *Before We Go* was his window to the 'very material realization that life is short, and you might die soon. This sense of limited time transforms a person, and everyone deals with it differently.' While León thinks experiential knowledge cannot be taught or explained, art can provide an outlet to exploring these experiences in an embodied manner (León 2020).

Nichols (2017, 150) also recognises that performativity can provide documentaries affective and embodied dimensions to explore experiences outside the sphere of language and conceptualisations. *Before We Go* offers no grand narrative, but it is constructed of fragmented scenes of various art workshops. In addition to the skeleton scene, we see, for example, interpretive dance scenes; a rendition of 'The Mercy Seat', performed in a service lift, where the singer proclaims to not be afraid of death; and an HIV patient with a history of drug use creating geometric shapes on coloured paper and looking out of the window through these shapes lit up by daylight – reminding him of the drug-induced hallucinations of his youth. In these scenes, embodied and artistic performances allow the viewer access to comforting scenes to experience mortality. The creative style's ability to act, to perform, was also noted in the film's reception. *The Hollywood Reporter*'s film critic Neil Young writes:

> While inescapably and unapologetically an artificial construct from the start, *Before We Go* provides ample rewards to those willing to suspend disbelief and go with its gnomic flow. The film operates at the extremities of life and emotion, places where anything goes and there's nothing to lose but pain and inhibition. (Young 2014)

This comment, similarly, acknowledges the performative power of embodied expressions where death anxiety is turned into productive and contemplative performances.

The ability to perform experiences shows that the filming process is not the sole source of ethical potential – this can also be found in the style and aesthetics. Edward Lamberti (2019, 19–22) argues that the viewer's ethical experience in performative documentaries is associated with the style, not only because it draws attention to the constructed nature of films, but also because it has the power to approach experiences where words fail us and still create expressions that resonate. The non-linguistic potential of cinema, which taps into the visceral aspects of human action, extends to showing ambiguous, disruptive and messy experiences. This rawness, according to Robert Sinnerbrink (2016, 3), evokes the viewer's philosophical and existential thinking, which in turn invites ethical experiences about being in the world.

In *Before We Go*, performances enable the subjects to portray what it is to live the acute understanding of impending death. The encounters become

embodied and affective stories about living with a sense of loss. At the beginning of the film, a few scenes take place outside the opera house. In one of them, Lidia wakes up at home and tries to get up. Her movements are tiny and slow and cause her pain. She sighs deeply when she tries to reach for her shoes. Next, she is having a bath, singing while washing herself. She emerges from the bathroom and holds onto the wall for support. The intimate scene exposes and embodies her fragility, limited mobility and living with pain. On arrival at the opera house, Lidia flings herself into an interpretive dance, where a professional dancer's fluid movements and loving caresses invite her to participate and express joy at being able to communicate through movement, no matter how minimal this movement may be. The dance scene grows to be an affective experience, because we have just witnessed how Lidia feels being limited by her body, and now, movement provides pleasure, not pain. León explains that this introductory scene to Lidia's life was based on their preparation workshops, where he had asked the participants to write about a typical day. Lidia dedicated three pages to describe waking up in the morning. The intimate scenes in the bedroom and bathroom force the viewer to pay attention to 'pain without identity, it is pain that you can't identify with, because you do not know the person who is suffering' (León 2020). The performance of pain turns into an experience of fragile mortality, as the film director's comment shows, an experience that can be co-shared by the subject and the viewer.

In *Before We Go*, the intellectual, cognitive or conceptual understanding of end of life is less important than the embodied and symbolic understanding of end-of-life experience. This decision forefronts the experiences of dying subjects, and there is no room for institutional or expert voices to explain their experiences for the viewer. Instead, the dying people are actively and knowingly creating and performing documentary content. The chosen mise-en-scène, La Monnaie, adds symbolic depth to the performances. The opera house is a place to perform, and was for the filmmaker a conscious choice of location. Not only is opera a stage, León (2020) argues, but it is also entwined with traditions of tragedy: people die and take their time dying on the opera stage. As such, the location adds symbolic elements to the staging of events, and to the embodied fantasies of mortality that were created together with filmmakers and co-creators. The artistic performances challenge the viewer to think and feel together with the images, with the performances. The performativity invites the viewer to see the end of life from someone else's unique perspective, and to recognise diversity in these experiences. By doing so, performative documentary builds a particular kind of avenue to ethical imagination, one where the viewer sees both the filmmaker's chosen perspective to the issue and also witnesses a film that has been actively co-created by the dying subjects. The experience of witnessing emphasises affective connection with the other.

Performativity and Affective Connection

While *Before We Go* paints fragmented scenes to emphasise how art can try to create a connection for the viewer to understand the experiences of the dying persons, Res Balzli's documentary film *Bouton* (2011) tells the story of one person, Johana, who has terminal breast cancer. Johana is a young actress who performs with an eponymous ventriloquist doll, Bouton. In his film review, Sven Zaugg (2011) describes *Bouton* as Johana's last leading role and creation. While I missed out on an opportunity to interview Balzli about the filming process (he died in 2019), Zaugg quotes the director's words: 'Precisely because she was an actress, we had the chance to create something with her, to even be able to repeat certain scenes' (Zaugg 2011, translated from German). In the film, performances are built in various ways: Johana performs on stage with Bouton, but she also performs her experiences for the viewer through the puppet and the imaginary conversations with three fairies – the past, the present and the future. *Bouton* uses performativity and theatricality to offer a unique and emotional story about death and dying, and provides profound insights into how performative documentaries can create a personal connection between the dying subject and the viewer.

First, Bouton the puppet gives access to Johana's thoughts and emotions. Bouton becomes an outlet for her to manage her fears and sense of losing the opportunities to live a full life. At the beginning of the film, Johana confides in Bouton (and in the viewer at the same time) that she is sick. The scene opens with Johana and Bouton sitting on a sofa. Johana is dialling her phone. Bouton hears static noise while Johana moves the phone above her breasts. Bouton follows the movement with vivid interest. After the call ends, Bouton asks who that was. In order to share, yet keep her secrets, Johana draws a blanket to cover them both. The viewer is left outside, but can hear a heartfelt discussion going on underneath the blanket. Johana explains that the phone sent her healing tones, which Bouton considers nonsense. While Bouton represents the other side of Johana, the argument shows both the doubt and the hope that alternative healing offers for Johana. She goes on to tell Bouton about her illness. The puppet had been aware that something was not right, confirming the intimate link between the two. To sympathise, Bouton claims to be feeling a bit under the weather as well. Johana is forced to admit that her illness is slightly more serious, a terminal cancer. Johana declares that she needs to fight. Bouton emerges from beneath the blanket and proclaims: 'You must not fight. You must rest. You are a princess.' Johana removes the blanket from her face and snuggles with Bouton: 'You are right. I would also like to rest.' This dialogue allows the viewer to follow Johana's conflicting inner thoughts and emotions – the desire to find a cure, being tired of fighting and longing to rest. 'Everything is magical with Bouton, nothing seems real,' Johana says, but it is

with Bouton that she gets most real. It is Bouton that gets to hear her deepest fears, regrets, hopes and desires. In this scene, Bouton also manages to coax Johana to uncover her illness – literally. From hiding her illness beneath layers (of blanket), Johana brings her secret fears of a shortened lifespan out in the open.

Bouton, in many ways, becomes an aid for Johana to perform her struggles with terminal illness, but at the same time, Bouton also provides the viewer access to Johana's inner thoughts. Brenda Werth argues that when an intimate testimony turns into a public performance, through film, for example, the viewer's focus shifts from questioning the authenticity of experiences to the affective elements of these experiences. The intimacy of self-expression encourages attachment, and in turn, the viewer's attachment transforms into a shared experience that reaches beyond the space of performance. For Werth, the created affective attachment can transcend 'boundaries between individual and collective subjectivities' (Werth 2013, quote from 94). In *Bouton*, while the viewer witnesses Johana going through cancer treatments, therapy and everyday moments, her performed experiences through Bouton the puppet encourage affective engagement.

Engagement with characters functions as a source of films' rhetorical power. Engagement is constructed by developing 'round', complex characters, giving them time and space in narration, providing subjective access to their thoughts and emotion, and presenting them in a morally favourable light (Smith 2022; Plantinga 2018b, 193–210). In *Bouton*, similar strategies invite the viewer to connect with Johana, the centre of the narration, while the performance enables the puppet to find a way to her inner world. The better the viewer gets to know her, the more unfair her situation feels. The viewer can feel compassion for her feeling of dying too young, in her early thirties, and not being able to experience what life has to offer, such as having children. Johana's dreams, wanting to become a mother and to entertain children with theatre, are both personally and socioculturally likable goals. In their experimental study on the reception of fictional characters, Elly Konijn and Johan Hoorn (2005) found that morally good, realistic and beautiful characters were most likely to encourage the viewer's positive engagement. Similarly, being a likeable, young and beautiful woman adds to the affectivity of tragedy in Johana's story.

Carl Plantinga argues that while encouraged closeness could be interpreted as a manipulative immersion into the story, the viewers' emotional connection with the characters should not be condemned but studied in context. The more complex the characters are, the more varied experiences the viewer is offered; the film's emotional appeal and power can lead to significant thought processes and discussion (Plantinga 2018b, 250). In documentary films, particularly, the use of complex characters creates both affective connections with the viewer and builds an ethical connection where the viewers can co-share

their experiences (Canet 2016; Plantinga 2018a). The construction of complex characters serves as an ethical act in giving the subjects a voice of their own. Neither the filmmaker nor anyone else speaks for the filmed subject, but the subject's own voice carves an opening for the viewer to understand the complexity of human experiences, such as what they might go through themselves if they were faced with an unexpected terminal diagnosis. And, as Johana's deep inner dialogues through Bouton show, moments of stylised and emphasised performances can be used to increase the complexity of the character in performative documentaries and thus add both to the authenticity and affectivity of the experience.

In *Bouton*, the magical meetings with three fairies enhance the sense of performativity and affectivity. Whereas Bouton the puppet stands by Johana through her everyday struggles, the fairies represent Johana's understanding of what death is and what might be beyond it. In these scenes, three themes emerge – time, journey and death – which are introduced in the opening image of the film. The three fairies are singing by the roadside memorial for a child. The road represents a journey, the fairies serve as the mystical elements of life and death, and the child's toys symbolise time, which is limited. In voiceover, Johana's and Bouton's dialogue is woven into the fairies' chanting when Johana explains to Bouton that even young people, such as children, can die. Johana, too, becomes an embodied example of having to let go of life too early.

These themes are developed further in a sequence halfway through the film. The sequence opens with winter scenery. Johana steps out on the snowy terrace and sits herself down in a lounge chair, holding on to a blanket and Bouton. Johana presses the puppet to her chest while resting, giving an impression of falling asleep. Shortly after, we hear Johana's voiceover: she is hurting, and this experience has taught her to understand those whose pain is so overbearing that they want to die. She stands up, as if she were sleepwalking, and asks what is left if you cannot enjoy the good things about life, good food and wine, laughter, making love. The scene cuts to three 'fairies', wearing white and sitting in a snowbank under a tree. They are chanting while Johana walks through the snow towards them, the puppet's suitcase with her. When Johana reaches them, they introduce themselves as past, present and future. The future fairy is holding a baby, a dream of Johana's that is now escaping her. Johana takes the fairies' place under the tree, when they disappear down the hill, chanting and dancing. The lyrical and poetic dream sequence rehearses the alliance of time, death and journey, but unlike the mournful atmosphere of the opening, this meeting with smiling and approachable fairies gives a promise of another realm that might be waiting for Johana after her pain and suffering ends. The fairies are not taking Johana with them yet, but their magical existence serves as a comforting pledge.

The last time the viewer meets the fairies is after Johana's death. Instead of a deathbed scene, where the viewer would witness dying, the film pictures Johana's death as a journey to another dimension, or as she describes it in the film, to 'another planet'. The metaphor of a journey is highlighted in two ways when Johana dies. First, her death is implied: her partner Lukas is performing to children at a hospital, where, after the happy clown performance, he withdraws to a dressing room, crying and singing a song to Johana, the love of his life. We then see Lukas sitting on a train, eating a sandwich on his way back from the performance. Mournful, he gazes out of the window at the grey scenery. He sits backwards, as if gazing into the past, into memories, while the train moves on, life continues, and future exists.

From this, the film cuts to the closing scene of the three fairies in a rowing boat. The fairy of the future leads the way, the present rows the boat and the past has a place at the rear, holding a beautiful umbrella. They row up the river, chanting. The image distances itself from them, and in an establishment shot, the viewer can see the boat towing a floating casket (Figure 6.2). In a staged performance, Johana is portrayed on her way towards a mystical journey beyond death, to another dimension. This ending symbolises the mysticism of death implied throughout the narrative. Here, the viewer is cut off from Johana, but is left with imagination and hope for her story to continue, leaving a positive, albeit melancholic, feeling. The ending becomes Johana's last performance – planned, stylised and affective.

Figure 6.2 Johana's last performance, a journey towards the unknown in *Bouton* (Balzli 2011).

Filmed Subjects and Performing Agency

Amy Hardie's documentary *Seven Songs for a Long Life* similarly engages with performativity in documentary-making by creating musical performances with hospice patients at Strathcarron Hospice in Scotland. Six patients get to perform for the camera the 'final songs' that fit their feelings, lives and personalities. The songs are made meaningful by the life stories of each participant, which bears a resemblance to *Bouton*'s way of building affective connection with the viewer through access to the dying subjects' personal experiences. In getting to know the performing patients, the viewer can also understand their song choices, which Hardie (2018) says are 'a way to people's inner worlds'. In this film as well, the performances and the supportive material offer an insight into the dying person's emotions, thinking and experiences.

Musical performances also make argumentative claims of the realities faced by dying people, and as such, the personal experiences turn into political notions about the sociocultural attitudes towards the end of life. In terms of Austin's speech act theory, all documentaries come into being through performance when they make some claim about the represented topic. However, Bruzzi (2010, 185–6) argues that performative documentaries add a layer to this act of 'performing claim', because they intentionally guide the viewer's attention towards acting for the camera, to the form and style of the documentary. These are purposefully used to advertise films' active agency in creating claims, or 'performing the actions they name'.

Seven Songs for a Long Life is introduced by Tosh, one of the six hospice patients. He performs three songs during the film, each one of them a Frank Sinatra standard. Tosh opens the documentary with his rendition of Sinatra's 'I Left My Heart in San Francisco' (Cory and Cross 1953). An impeccably dressed gentleman, he sits in a chair, slightly turned away from other patients, who are participating in an arts and crafts session. Facing the camera, occasionally even looking straight at the camera and acknowledging the viewer by returning the gaze, Tosh sings about the past glory of cities, being lonely and abandoned, and going home (Figure 6.3). The scene sets the stage for what follows, welcoming the viewer to the world of the hospice where the patients are prepared to perform, willing to be heard and seen as active, living persons. The stage-like setting and reciprocal gazing highlight the subjects' willing participation in the creative and ethical process of filming, and access to a unique embodied and affective experience that invites ethical connection. Furthermore, through performative scenes with music and singing, the documentary 'performs' a claim about life's end as a meaningful phase of life.

Music has a contested role in the documentary field. The influential *cinéma vérité* style favours sounds of fuzziness, background noise and talking to give an impression of authenticity and non-produced documentary films (Paget and

Figure 6.3 Opening of *Seven Songs for a Long Life* where Tosh sings during an arts and crafts session (Hardie 2015).

Roscoe 2006; Corner 2002). Yet, similarly to fiction films, music can drive the narrative, link different scenes together and provide emotional texture to the film by intensifying the viewer's engagement with the images (Corner 2002; Nichols 2016, 92). In documentary musicals such as *Seven Songs for a Long Life*, songs refuse to remain in the background. Instead, they become an integral part of the documentary musical, adding to its mediated experiences, as Derek Paget and Jane Roscoe argue. They continue that while the active and performative use of songs has an impact on the experience and mediated information (as does a soundtrack in general), it also gives the film a sense of theatricality (Paget and Roscoe 2006).

Theatricality is recognisable in another song by Tosh, where he asks a fellow patient to duet 'Strangers in the Night' (Kaempfert, Singleton, and Snyder 1966). Together, they flirt for the camera and put on a show. The images of them having a laugh are edited together with scenes of Tosh having a haircut at the hospice salon, as if getting ready for a night of romance and dating. The montage-like section confirms that even though the two are singing for those in the hospice common room, the film viewer remains the primary audience. The viewer is allowed to witness the preparations and is invited to step into the spaces of theatricality. Theatricality is also present in saying goodbye to Tosh, who died during the filming. The viewer can hear his interpretation of 'The Good Life' (Distel and Reardon 1962), but instead of seeing Tosh, the camera is back at the salon, where a lonely seat mediates the sudden departure that leaves emptiness in its wake. The song touches upon all the experiences that

life has to offer, and the loneliness and longing that goes along with the journey (Distel and Reardon 1962). The lyrics of discovering the unknown and bidding the good life farewell embrace the bittersweet reluctance to let go of life.

Tosh's musical moments, similarly to *Before We Go*, are carefully planned, rehearsed and filmed. Yet, these moments have an indexical relationship with Tosh's lived experiences. Amy Hardie, the filmmaker, reminisces that the idea of the documentary took form when she met Tosh the storyteller:

> He came from such a tough background. He had been working since he was thirteen. His father had died when he was two. He had had so little money. And he said, the only thing I got, the only thing when anyone paid attention to me was when I started singing when I was thirteen. (Hardie 2018)

Hardie had asked Tosh to sing for her. The film idea grew from these small encounters, from stories such as Tosh's dreams, 'his longing for a bigger world to be part of, the world of Frank Sinatra' (Hardie 2018). In the documentary, Tosh's longing shifts beyond performing personally meaningful songs to become an act of empowerment. Performativity gives him visibility. The film is his last stage to being validated and acknowledged by local, national and even global audiences.

Tosh is not alone with his feeling of invisibility. Iain, who has multiple sclerosis (MS), talks about his loneliness in a voiceover while walking the corridors of the hospice:

> When you get MS you get disconnected from everybody because all your friends disappear. A lot of them don't get back to you anymore, they just don't communicate anymore. A lot of them don't even understand what MS is and half of them think they can get it. (Hardie 2015)

These experiences speak to the social marginalisation that many severely ill people encounter. The marginalisation of terminally ill people is conceptualised through 'social death', a concept familiar from social history, at its most striking in slavery and genocide, where a person's social influence and vitality have ended, even if they are still physically alive (Card 2003; Mulkay 1993; Patterson 1982). 'Social death' has been extended to describe the institutionalised old, ill and dying people whose interaction with other people and ability to make decisions about their daily lives become limited. They are forced into the liminal state of social death, which ends at physiological death (Brennan 2019; Sweeting and Gilhooly 1992). At the end of life, it is not only the institutions that can produce the social death of their patients, but marginalisation can extend to social relationships as Iain's and Tosh's concerns disclose.

There is frustration in the situation where they still have plenty to give, but others, perhaps out of fear, refuse to understand this. Their musical performances are both emotional self-expressions and acts of (re)claiming their place as members of the public.

Rather than being a mere colourful addition to the documentary about end-of-life experiences, the performances become the means of validating the film's claim about the agency of the terminally ill. Hardie recalls how the filming process turned into a co-creation with the filmed subjects, who were managing their self-expression by performances and were simultaneously inspired by the possibility of the film contributing to the world. The filming allowed them to recognise themselves as people who can 'create and contribute pleasure and value' (Hardie 2016, 260). Their ability to co-create musical performances gave them an active role in public discussions about end of life.

That the terminally ill have agency is a response to some public discussions in the early twenty-first century, when documentary and reality television representations of end of life began to take hold. The debate was commonly framed by concerns over exploiting vulnerable persons' privacy (Gibson 2011; Hakola 2013). For example, Kevin David Kendrick and John Costello argued that the BBC's reality series *Nurse* exploited the ill and infirm, potentially endangering their capability to make conscious choices. Moral compassion should be more important than the viewers' option to witness intimate moments in the name of public access, education or demystifying anxiety related to illness and death (Kendrick and Costello 2000, 16–20). These claims have been met with counter-arguments, where the participation of dying people is seen as an empowering and a meaningful social engagement (Horne 2013; Fox 2011; Haraldsdottir 2017; West 2018). The theatrical performances in *Seven Songs for a Long Life* make clear that the dying are conscious of the presence of the camera, the filmmaker and, consequently, the viewer. Tosh and Iain, for example, urge the viewer not to understand their vulnerable positions as lack of agency. In a way, they hold up a mirror to the viewer: you claim to protect our privacy, but are you just avoiding being reminded of your own mortality and temporary nature of life?

These notions for the need to validate the agency of the dying are supported by Erna Haraldsdottir's observational study of Hardie's filming of *Seven Songs for a Long Life*. Haraldsdottir found that the hospice patients did not want to dwell on death and dying. Instead, they wanted to tell their life stories, share their dreams and give people insight into their daily lives. As Haraldsdottir contends, these notions also reproduce the ideology of the hospice movement about empowering the dying, openness about death and the healing impact of engagement. It is here that art projects can offer ways of coping with difficult emotions (Haraldsdottir 2017). Naomi Richards (2013, 199, 201), who has ethnographically studied film art projects at other British hospices, similarly emphasises that performative stories give dying subjects an opportunity to

leave an empowered testimony of themselves by creating something positive and meaningful. Performativity can thus give voice and agency to the dying subjects, resist social marginalisation and, at the same time, invite the viewer to be part of the engaging and empowering experience through witnessing the other in their own terms.

Positive empowerment also makes an emphatic point about being alive. According to Richards (2013, 193), hospice-based film projects connect with the hospice movement's desire to help patients to 'live until they die'. This the hospices do by providing activities, empowerment and person-centred care. For Amy Hardie, the attitude of 'living until you die' was a conscious and goal-oriented choice in the filmmaking. She argues that life, not death, is what defines us (Hardie 2018). In one particular scene, hospice nurse Mandy Malcomson discusses this ideology in a voiceover: 'Even when people come to us and they're told they're dying, to me they're still living.' She explains this through her own experience. She used to work in intensive care, but the longer she worked there, the more she wanted to connect with the person in bed, behind all the technology. The hospice environment enables her to do this, to connect, for example, with music, which is one of the last things that the brain remembers. In this documentary, then, singing also becomes a performance about life. While the documentary also includes intimate moments of the subjects reflecting on their uncertain futures or experiencing pain and suffering, the subjects are determined to keep making memories. Participation in a documentary musical becomes a way of embracing life.

Life-Affirming Viewing Experience

The life-affirming performances also exist for the sake of the viewer. If the viewers are willing to engage with the subjects, to open up for their experiences and to validate their agency, the subjects give a comforting promise in return that the end of life is not a meaningless phase of life and waiting to die, but it can also be fun, engaging and worthy of memories. Based on fiction films, Diana Rieger and Matthias Hofer (2017) contend that 'meaningful films' dealing with existential questions, such as death, have the potential to manage death anxiety. In their experimental study, films that emphasise life instead of death efficiently prove coping mechanisms: the survival of characters in life-threatening situations confirms the meaning of life for the viewers and reduces their death anxiety (Rieger and Hofer 2017). In end-of-life documentaries, life-threatening illnesses are neither cured nor solved, yet performative documentaries offer life-affirming experiences in their own ways. First, to be able to perform, the filmed subjects are in good physical condition and active. There are not too many physical reminders of mortality. Second, the subjects' deaths are not shown to the viewer. In *Seven Songs for a Long Life*, for

example, death is communicated through absence, as in the case of Tosh, or in the final credits listing the dates of death. The on-screen subjects remain full of life. Thus, in a roundabout way the documentary engages the viewer with the topic of mortality, while the life-affirming tone provides a safe and comforting distance from the topic.

Both Naomi Richards (2013, 202) and Jennifer Malkowski (2017, 107) argue that life-affirming representations enable the viewer's cathartic release. Dying can be witnessed at a safe distance from the frail dying bodies, and this distance makes the films watchable and approachable. For Amy Hardie, the positive narrative tone is both welcomed and needed. Audiences might be anxious about death and would thus avoid a documentary about the topic, says Hardie, but the positive tone of the musical performances suggest that there is potential for connection:

> I wanted the film to allow the audience to get in that place in their own heads where they could bear that confrontation. And I realised music was one way to let me do that. Because singing is so pleasurable that it lets you get over the discomfort when thinking about death. (Hardie 2018)

The audience appears to accept this choice and demonstrated it in their positive responses (Haraldsdottir 2017, 271; Hardie 2016, 261–3). Even a quick look at the reviews of Hardie's documentary supports these notions. The reviews recognise the difficulty of the topic – facing death – but praise the documentary as 'incredibly moving' thanks to its 'honesty, dignity and affection' (Felperin 2015). They also see the documentary as 'heart-warming, life-affirming' (Carson 2017), 'heart-affecting', 'magical', 'mesmerising' (Brussat and Brussat 2017) and 'charming, soulful and bittersweet' (Bär 2015). It is a film that 'intimately' explores 'the vitality of life' (Bär 2015). Even these few examples show that the reviewers are positively surprised by the positive emotions that the dying people are represented with.

Hardie (2016) argues that the combination of positivity and performativity gives her documentary its transformative power which can help people to deal with death anxiety. She sees this transformation take place both on-screen and off-screen. In the course of the filming, she found that the functions given to singing by the participants changed during the process. At first,

> [t]he songs were used as a distraction from illness, from the experience of being a patient. The performances were a way of proving to themselves and those around them that they were more than 'patients'; that they were still people with dreams and desires. They used the songs to distract themselves and the hospice audience from the possibility of death. (Hardie 2016, 259)

The participants used their chosen songs for self-expression and agency, but the very choosing of the songs turned to self-exploration of their mortality: 'In the last year of filming the patients began to use song to reflect on their fears and hopes around end of life' (Hardie 2016, 260). In the film's reception, evaluated in an audience questionnaire after the screenings, Hardie recognises a similar transformation from escaping mortality to engaging with it. At first, the songs give the audience an easy entrance to the story, but they also help the audience members to discuss death with others, to feel more confident to think about their mortality and to feel less anxious about the hospice and death. Most of all, Hardie claims, the film gave the audience members a sense of hope that the end of life can be a meaningful phase of living (Hardie 2016, 262–4). The seemingly 'escapist' or 'distancing' use of songs can discreetly entice the viewers to encounter their own mortality. It may also alleviate anxiety (if not about death, perhaps about hospice care).

Such transformations in attitudes and beliefs, whether permanent or temporary, are often desired outcomes of documentary films and the performative claims about their topics. In addition, these transformations are at the very core of the documentaries' ethical aspects. At its best, as Hongisto argues, documentary ethics means more than ethical procedures of filming; it is the ways in which these films imagine, 'fabulate' and create affection. The documentaries can propose meanings and create potential for realities that are to come (Hongisto 2015, 135–7). In the case of end-of-life documentaries, these films can propose a society which is open to engaging with death and mortality and which acknowledges the dying persons as valid members of society and social relationships.

Conclusion

Seven Songs for a Long Life, *Before We Go* and *Bouton* all make the life-affirming claim of a meaningful end of life through highlighted performativity. Artistic performances can enchant the viewer, but they can also serve as comments on social issues. According to Paget and Roscoe (2006), the performative documentary can break free from the history of seriousness and step into the realm of melodrama, yet it is not a diversion from the 'real' story, but the very core of the text. The use of joyous musical scenes, interpretative dances or magical fairies as life-affirming performances enables performative documentaries to make claims of dying persons' agency and end of life as a meaningful phase of life. On-screen, Tosh, Iain, Lidia, Johana and others become rounded and complex personalities who promise the viewer that the end of life is not only about waiting to die, but about life. These personalities should not be marginalised and excluded from social interaction. They should rather be included, acknowledged and appreciated. The performative scenes which are

supported by anecdotes of the subjects' lives give these claims discretion; the viewers are not preached to or lectured. Instead, they are allowed to create a personal connection with their experiences, and these connections, then, can turn into ethical imagination and transformed attitudes.

In performative documentaries, the terminally ill people are active and in good enough physical condition to participate in filming, which is not always the case with patients in palliative care. The decision to film active people is related to the ethics of filming – the active participation already suggests that the subjects have consented to being filmed – and to the life-affirming goals of these documentaries. The filming of dying people who are well enough follows contemporary cultural practices, where, for example, memorial photographs represent lively and often young persons. In this way, the person can live forever through images, and the preserved moments push any reminders of mortality, death, dying or dead bodies to the margins (Walter 2015, 225; Aceti 2015, 319–27; Bennett and Huberman 2015). In film theory, André Bazin calls this process a 'mummification effect', which refers to the camera not only recording change but having the power to replay and repeat that change in photographic images. Cinema can eternally kill characters and then bring them back to life by replaying the scenes. This is how the cinema can mummify change and 'embalm time' (Bazin 1960). Every time the viewer restarts the film, Johana and Tosh, for example, are back to their active selves, death only as a forever anticipated outcome. Thus, even if *Bouton*, for example, is a story about end of life, it becomes a performance about life.

This kind of life-affirming approach has had a mixed response. Richards, for example, recognises that the positive tones of these kinds of films can support the hospice movement's desire to focus on living, not on the life-limiting aspects of dying, and that these projects can empower the dying persons and support their well-being. Still, the life-affirming documentaries also freeze a person's representation (and their physical decline) in time, as the footage conveys a sense that everything is happening now (Richards 2013, 193, 197–8). The life-affirming tone of performances crops physical frailty out of the picture, instead focusing on the scenes where the subjects remain active. We are therefore back to ethical questions of authenticity raised at the beginning of this chapter. The question is whether performative documentaries give a realistic representation of dying or whether it idealises these processes and builds unrealistic expectations. And certainly, in one way, the life-affirming documentaries offer a limited vantage point on the dying process, yet this view is not any less authentic in its claims. It merely creates one perspective to the topic of end of life, and this perspective performs an argument that the dying persons have plenty to give while they are alive and that living does not end with a terminal diagnosis. Thus, while it might not be a full image – how would we even define a 'full image'? – it does constitute

a positively framed invitation to think about mortality in a world where fear and anxiety commonly lead to our avoiding the topic. Thus, for many, these films can be the start of a meaningful conversation, not the only representation they ever encounter about dying.

References

Aceti, Lanfranco. 2015. 'Eternally Present and Eternally Absent: The Cultural Politics of a Thanatophobic Internet and Its Visual Representations of Artificial Existences'. *Mortality* 20 (4): 319–33. https://doi.org/10.1080/13576275.2015.1085297.

Austin, J. L. 1975. *How to Do Things with Words*, edited by Marina Sbisà and J. O. Urmson. First published 1962. Oxford: Clarendon.

Bakhtin, M. M. 1984. *Rabelais and His World*. First published 1965. Bloomington: Indiana University Press.

Balzli, Res. 2011. *Bouton*. Documentary. First Hand Films.

Bär, Daryl. 2015. 'Review: Seven Songs For A Long Life'. *Film Reviews, Interviews, Features | BRWC* (blog). 19 October 2015. https://battleroyalewithcheese.com/2015/10/review-seven-songs-for-a-long-life/. Last accessed 12 April 2022.

Bazin, André. 1960. 'The Ontology of the Photographic Image'. Translated by Hugh Gray. *Film Quarterly* 13 (4): 4–9. https://doi.org/10.2307/1210183.

Bennett, Jeffrey, and Jenny Huberman. 2015. 'From Monuments to Megapixels: Death, Memory, and Symbolic Immortality in the Contemporary United States'. *Anthropological Theory* 15 (3): 338–57. https://doi.org/10.1177/1463499615575943.

Brennan, Michael. 2019. 'Social Death'. In *Non-Death Loss and Grief*, edited by Darcy L. Harris, 36–49. New York; London: Routledge.

Brussat, Mary Ann, and Frederic Brussat. 2017. 'Seven Songs for a Long Life, Film Review'. Spirituality & Practice. 2017. https://www.spiritualityandpractice.com/films/reviews/view/28362/seven-songs-for-a-long-life. Last accessed 12 April 2022.

Bruzzi, Stella. 2010. *New Documentary*. First published 2000. London; New York: Routledge.

Canet, Fernando. 2016. 'The Filmmaker's Engagement with the Subject in Contemporary Documentary: *Foreign Parts* as a Case Study'. *Studies in European Cinema* 13 (2): 149–62. https://doi.org/10.1080/17411548.2016.1213582.

Card, Claudia. 2003. 'Genocide and Social Death'. *Hypatia* 18 (1): 63–79. https://doi.org/10.1111/j.1527-2001.2003.tb00779.x.

Carson, Diane. 2017. '"Seven Songs for a Long Life" Affirms Life'. KDHX. 1 April 2017. https://kdhx.org/articles/film-reviews/439-seven-songs-for-a-long-life-affirms-life. Last accessed 12 April 2022.

Cave, Nick, and Mick Harvey. 1988. *The Mercy Seat*. Music album.

Corner, John. 2002. 'Sounds Real: Music and Documentary'. *Popular Music* 21 (3): 357–66.

Cory, George, and Douglass Cross. 1953. 'I Left My Heart in San Francisco'. Song.

Distel, Sacha, and Jack Reardon. 1962. 'The Good Life'. Song.

Felperin, Leslie. 2015. 'Seven Songs for a Long Life Review – Going down Singing'. *The Guardian*, 1 October 2015. https://www.theguardian.com/film/2015/oct/01/seven-songs-long-life-review-honesty-documentary-hospice-dying. Last accessed 12 April 2022.

Fox, Broderick. 2011. 'The Final Cut: End-of-Life Empowerment through Video Documentary'. In *Exploring Issues of Care, Dying and the End of Life*, edited by Sue Steele and Glenys Caswell, 55–62. Leiden: Brill. https://doi.org/10.1163/9781848880580.

Gibson, Margaret. 2011. 'Real-Life Death: Between Public and Private, Interior and Exterior, the Real and the Fictional'. *South Atlantic Quarterly* 110 (4): 917–32. https://doi.org/10.1215/00382876-1382321.
Hakola, Outi. 2013. 'Normal Death on Television: Balancing Privacy and Voyeurism'. *Thanatos* 2 (2): 32.
Haraldsdottir, Erna. 2017. 'Enhancing Openness around Death and Dying through Documentary Film-Making in a Hospice'. *European Journal of Palliative Care* 24 (6): 268–71.
Hardie, Amy. 2015. *Seven Songs for a Long Life*. Documentary. SDI Productions.
———. 2016. 'Movie-Making as Palliative Care'. In *On the Feminist Philosophy of Gillian Howie: Materialism and Mortality*, edited by V. Browne and D. Whistler, 247–65. London: Bloomsbury Academic.
———. 2018. Personal interview by Outi Hakola.
Hongisto, Ilona. 2015. *Soul of the Documentary*. Amsterdam: Amsterdam University Press. https://doi.org/10.5117/9789089647559.
———. 2018. 'Realities in the Making: The Ethics of Fabulation in Observational Documentary Cinema'. In *Storytelling and Ethics*, edited by Hanna Meretoja and Colin Davis, 190–9. New York: Routledge.
Horne, John. 2013. 'Unsettling Structures of Otherness: Visualising the Dying Individual and End of Life Care Reform'. In *Envisaging Death: Visual Culture and Dying*, edited by Michele Aaron, 224–42. Newcastle upon Tyne: Cambridge Scholars Publishers.
Kaempfert, Bert, Charles Singleton, and Eddie Snyder. 1966. 'Strangers in the Night'. Song.
Kendrick, Kevin David, and John Costello. 2000. '"Healthy Viewing?": Experiencing Life and Death through a Voyeuristic Gaze'. *Nursing Ethics* 7 (1): 15–22. https://doi.org/10.1177/096973300000700104.
Konijn, Elly A., and Johan F. Hoorn. 2005. 'Some Like It Bad: Testing a Model for Perceiving and Experiencing Fictional Characters'. *Media Psychology* 7 (2): 107–44. https://doi.org/10.1207/S1532785XMEP0702_1.
Lamberti, Edward. 2019. *Performing Ethics through Film Style: Levinas with the Dardenne Brothers, Barbet Schroeder and Paul Schrader*. Edinburgh: Edinburgh University Press.
León, Jorge. 2014. *Before We Go*. Documentary. Films de Force Majeure.
———. 2020. Personal interview by Outi Hakola.
Malkowski, Jennifer. 2017. *Dying in Full Detail: Mortality and Digital Documentary*. Durham, NC; London: Duke University Press.
Mulkay, Michael. 1993. 'Social Death in Britain.' In *The Sociology of Death*, edited by David Clark, 31–49. Oxford; Cambridge: Blackwell Publishers.
Nichols, Bill. 2016. *Speaking Truths with Film: Evidence, Ethics, Politics in Documentary*. Oakland: University of California Press. https://www.jstor.org/stable/10.1525/j.ctv1wxtcp.
———. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.
Paget, Derek, and Jane Roscoe. 2006. 'Giving Voice: Performance and Authenticity in the Documentary Musical'. *Jump Cut: A Review of Contemporary Media*, no. 48. https://www.ejumpcut.org/archive/jc48.2006/MusicalDocy/index.html. Last accessed 11 April 2022.
Patterson, Orlando. 1982. *Slavery and Social Death: A Comparative Study*. Cambridge, MA: Harvard University Press.
Plantinga, Carl. 2018a. 'Characterization and Character Engagement in the Documentary'. In *Cognitive Theory and Documentary Film*, edited by Catalin Brylla

and Mette Kramer, 115–34. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-90332-3_7.

———. 2018b. *Screen Stories*. Oxford: Oxford University Press. https://doi.org/10.1093/oso/9780190867133.001.0001.

Pratt, Mandy, and Michele Wood, eds. 2015. *Art Therapy in Palliative Care*. First published 1998. London: Routledge. https://doi.org/10.4324/9781315788012.

Pryluck, Calvin. 2005. 'Ultimately We Are All Outsiders: The Ethics of Documentary Filming'. In *New Challenges for Documentary*, edited by Alan Rosenthal and John Corner, second edition, 194–208. Manchester; New York: Manchester University Press.

Richards, Naomi. 2013. 'Rosetta Life: Using Film to Create "Bearable Fictions" of People's Experiences of Life-Limiting Illness'. In *Envisaging Death: Visual Culture and Dying*, edited by Michele Aaron, 190–205. Newcastle upon Tyne: Cambridge Scholars Publishing.

Rieger, Diana, and Matthias Hofer. 2017. 'How Movies Can Ease the Fear of Death: The Survival or Death of the Protagonists in Meaningful Movies'. *Mass Communication and Society* 20 (5): 710–33. https://doi.org/10.1080/15205436.2017.1300666.

Safrai, Mary B. 2013. 'Art Therapy in Hospice: A Catalyst for Insight and Healing'. *Art Therapy* 30 (3): 122–9. https://doi.org/10.1080/07421656.2013.819283.

Sinnerbrink, Robert. 2016. *Cinematic Ethics: Exploring Ethical Experience through Film*. London; New York: Routledge.

Smith, Murray. 2022. *Engaging Characters: Fiction, Emotion, and the Cinema*. First published 1995. New York: Oxford University Press.

Sweeting, Helen N., and Mary L. M. Gilhooly. 1992. 'Doctor, Am I Dead? A Review of Social Death in Modern Societies'. *OMEGA – Journal of Death and Dying* 24 (4): 251–69. https://doi.org/10.2190/L0N6-P489-NR8N-JQ6K.

Walter, Tony. 2015. 'Communication Media and the Dead: From the Stone Age to Facebook'. *Mortality* 20 (3): 215–32. https://doi.org/10.1080/13576275.2014.993598.

Werth, Brenda. 2013. 'A Malvinas Veteran Onstage: From Intimate Testimony to Public Memorialization'. *South Central Review* 30 (3): 83–100.

West, Emily. 2018. 'Invitation to Witness: The Role of Subjects in Documentary Representations of the End of Life'. *International Journal of Communication* 12: 1481–500.

Young, Neil. 2014. '"Before We Go": Marseille Review'. *The Hollywood Reporter* (blog). 9 July 2014. https://www.hollywoodreporter.com/movies/movie-reviews/before-we-go-marseille-review-717379/. Last accessed 22 September 2022.

Zaugg, Sven. 2011. 'Das Sterben hat keine Logik'. St. Galler Tagblatt. 16 April 2011. https://www.tagblatt.ch/kultur/film/das-sterben-hat-keine-logik-ld.2054104. Last accessed 16 September 2022.

7. LEGACY DOCUMENTARIES

Reaching beyond Death

Helen's Story (Davidson and Gibb 2016), a New Zealand documentary, is the story of a young mother with terminal cancer. Devastated by the limited time she has left, Helen wants to leave her children a special memory. She asks filmmakers Paul Davidson and Barbara Gibb to record her last months. During these months, the filmmakers let Helen make her voice heard, to have control over her life and death, and, as Gibb says, to 'enable her legacy' (Davidson and Gibb 2020). By giving meaning to Helen's life story and by building a legacy that reaches beyond death, this end-of-life documentary helps to make death bearable.

Legacy translates into how and for what a person will be remembered. As such, it engages with the meaning-making of one's life at its end (Boles and Jones 2021; Breitbart 2016; Hunter 2008). Legacy has been conceptualised in contexts of continuing social bonds. The legacies of those who came before us (parents, ancestors, society) influence our values, norms, traditions, and spiritual and cultural knowledge, while our legacies influence those who come after us (Breitbart 2016; Hunter 2008). Legacies which are passed on beyond death, are part of an evolving continuum. Documentary projects give personal legacies a wider audience, and turn something personal into something public; they leave a mark on historical and social communities.

Creating a legacy through documentary film is an act that reaches beyond death, towards symbolic immortality. The term originates from Robert Jay Lifton and Eric Olson (1974), referring to the desire to be publicly remembered

by the following generations. This memorialisation is attempted through public artefacts, such as monuments and statues, or by having one's name written in history books or by creating lasting art, such as films (Longfellow 2013; Werth 2013). Being the protagonist of a documentary film about oneself becomes a recognition of existence, which is evident in Paul Davidson's perspective: 'I think we enabled Helen to live on in a film. Helen can be alive in that way as long as she likes' (Davidson and Gibb 2020). Symbolic immortality, thus, gives comfort that some part of us lives on, and death is not the end of a person's social influence. Jeffrey Bennett and Jenny Huberman argue that the promise of symbolic immortality can alleviate death anxiety, particularly a form of death anxiety that stems from forced disconnection from others and the world through bodily failure. While the biological aspects of death remain a reality, people have searched for ways to cross the limits between life and death and to continue to be connected to those left behind (Bennett and Huberman 2015, 340–1). Any form of memorialisation ensures continuing social bonds, yet a publicly built symbolic immortalisation creates an open legacy for a person's life, actions, values and beliefs.

Because legacies are built in historical and sociocultural contexts, they are connected to social norms, values, attitudes and practices. Elizabeth Hunter observes that legacies can be positive, negative or something in-between. Also, some persons are more conscious of their potential legacies, and they plan what belongings, actions or values they would like to share and pass along (Hunter 2008, 325). This self-reflective practice can aim for idealised versions of ourselves, a polished image of how we want to be viewed by future generations (Bennett and Huberman 2015; Carter 2007). The documentary films can provide a medium for these practices where the subjects self-memorialise and self-moralise their actions, and where these representations are evaluated by the viewers. Catalin Brylla and Mette Kramer (2018), for example, argue that because documentary films invite the viewer to engage with the filmed subjects, this practice includes the viewer's evaluation of whether the filmed subject is a morally and socially acceptable character. A moral evaluation is needed for the viewer to engage and to create an allegiance, a deep connection, with any character. The evaluation emphasises the character's behaviour in relation to moral norms and social expectations (Smith 2022, 187–93). In an ethical perspective on cinema, the characters do not need to be morally valued to encourage ethical thinking in the viewer, because both morally questionable and morally celebrated actions inspire emotional, embodied and cognitive evaluation of social norms and expectations. Similarly, both positive and negative legacies – or those which are something in-between – can turn into morally and ethically engaging stories for the documentary viewer.

In this chapter, I analyse end-of-life documentary films where legacy-building underpins the filmmaking and viewing. These films typically memorialise one

person at a time to highlight their unique experiences and legacy. In addition to *Helen's Story* (Davidson and Gibb 2016), a New Zealand documentary about a half-white and half-Māori woman, the analysis draws from the American documentary *Prison Terminal: The Last Days of Private Jack Hall* (Barens 2013), which portrays Jack's death at a prison hospice; and a Finnish documentary *Marika's Passing* (Wallenius 2021a), where terminally ill Marika is preparing for death.

I interpret these documentaries both as 'belongings' and 'actions', based on Hunter's (2008, 318) argument that legacies can be transmitted through materiality, such as memorials and monuments, and through actions and their consequences. In the case of end-of-life documentaries, the materiality of the film, including the arguments it performs, represents 'belongings'. These include, on the one hand, the personal legacy-building of the filmed subject, and, on the other hand, the general legacy of the documentary, or in other words, its claim for end of life. In terms of actions, three actors participate in the legacy-building. First, the filmed subjects create their legacies by active participation in filming. Second, filmmakers enable these personal processes and use them to create an argument – a legacy – for the film. And third, through witnessing and evaluation, the viewer either actualises or disowns the suggested legacies. Thus, the belongings and activities related to constructing and mediating legacies through documentary films are complex, and each aspect brings different ethical or moral questions into play.

Filmed Subject and Morality of Legacy-Building

In hospice and palliative care contexts, organising legacy-oriented activities is part of the therapeutical care practices where patients can give meanings to lived lives. Legacy-building activities, such as writing journals, encouraging storytelling, creating scrapbooks and filming life stories increase the patients' well-being and reduce the symptoms of depression (Boles and Jones 2021). The legacy activities come under the umbrella of 'narrative therapy', which emphasises reviewing one's life at such moments as being diagnosed with an illness, when the need for self-reflection and reconstructing one's life story arises (de Muijnck 2019, 63; Fioretti et al. 2016). Besides legacy, 'autobiographical work' and 'narrative identity' are used to describe the ongoing processes where we tell stories about ourselves, our lives and our values to ourselves and others. Autobiographies are consciously made reflections of self that often assume an audience, thus mixing private and public spheres (van Dijck 2004), while narrative identity refers to both conscious and unconscious processes where we construct our identities through storytelling. This involves facticity and fabulation as well as continuity and change (Ricœur 1980; Rimmon-Kenan 2002; Ricœur 1992; McAdams 2011; Hunter 2008). All these forms of life

narratives can deepen our understanding of ourselves and our experiences, where we come from, where we are going and who we are.

Despite the similarities, or sometimes interchangeable uses of 'legacy', 'autobiography' and 'narrative identity', these concepts vary in their assumptions of an audience and temporality. Legacies are created with others in mind, because others validate what we consider worth remembering about ourselves. Mediated autobiographies are statements of self that assume, but do not require, someone witnessing (van Dijck 2004). And narrative identity constructs our sense of self primarily to ourselves and secondarily to others. The narrative identity is an ongoing process throughout a person's life, where continuity is created between the past, the present and an anticipation of the future (McAdams 2011, 100; Rimmon-Kenan 2002, 11–12, 22–3). The need for reconstructing the identity often arises from a disruptive experience, such as a life-threatening illness, when we need to change our anticipation of the future and re-imagine what our lives will be. Autobiographies, in turn, are acts of memories and remembering (van Dijck 2004), and as such they focus on explaining the past. In contrast, legacy builds around mortality and death. While legacy is also about identity and remembrance, it anticipates a posthumous future, where others have the power to either validate or reconstruct our legacy-building.

For the dying subjects, participation in end-of-life documentaries where the narration is based on their life stories provides a venue to build their personal and public legacies. For Private Jack Hall, for example, the filming of *Prison Terminal*: *The Last Days of Private Jack Hall* (Barens 2013) serves as a possibility to reconcile his troubled identity and ask for social redemption in front of the public. The film opens with Jack confessing that he ended up in prison for killing a dealer whom he suspected of selling drugs to his son. His declining health has made him aware that 'I get out of here one day. In a box.' His acute sense of mortality strengthens an inner conflict when he starts reflecting on how he will be remembered. What legacy will he leave behind?

First, the documentary's claims become a part of Jack's legacy, a thought that comforts him, according to film director Edgar Barens (2019). *Prison Terminal* taps into Jack's story to shed light on incarceration practices in the US. The film illustrates the aging prison population and how, due to long prison sentences, many prisoners die within these institutions. Some prisons, such as Iowa State Penitentiary, where the film was shot, have started hospice programmes to deal with the issue. The documentary uses Jack's experiences as an example of the benefits and practices of these programmes. Barens (2019) argues that he cannot claim that his film has led to dozens of new prison hospices, but it did start at least five: 'At least I can say that I know that a lot people have died better than they would have normally died in prison, and the film is still out there doing a lot of good work.' Furthermore, Barens argues that Jack helped

to create the film's legacy, its argument for prison hospices: 'He knew what the film was about, and I asked Jack, do you want to be part of this film? He said, "absolutely". I think he was leaving a legacy for other prisoners, and he felt honoured in a way' (Barens 2019). This legacy, Barens emphasises, extends to other subjects in the film, the prisoners who volunteered at the hospice when Jack died. They helped to make changes in incarceration care practices, and Barens argues that knowing this means a lot to him and the volunteers (Barens 2019). Thus, *Prison Terminal* combines arguments for enabling a dignified death for the incarcerated population together with providing opportunities for prisoners to create a meaningful legacy.

In addition to this general legacy, the documentary also enables Jack to build his personal legacy, which is a more troubled process. Jack is afraid of what happens after he dies, both regarding whether his punishment will continue in the afterlife (punishment for sins) and how he will be remembered. Jack expresses a strong desire to rewrite his legacy to include positive aspects. This process compares to Dan McAdams's argument that 'redemption' functions as a building stone for 'good life' and 'generativity script', where a person achieves positive legacy and leaves a valuable legacy. Consequently, many life narrations have built-in morality. People tend to highlight elements of their lives that society can interpret as signs for a 'good and worthy life' (McAdams 2011, 110). Deborah de Muijnck (2019, 49, 57, 64), similarly, observes that the forthcoming death can trigger a person to self-reflect on their choices and values from a moral perspective in order to experience, or at least express, a sense of personal growth, a socially worthy goal in life. For Jack, his impending death inspires legacy-building, whereby he embarks on a moral evaluation and redemption of his life choices and invites the viewer to join him on a journey of personal growth.

As the opening of *Prison Terminal* shows, Jack does not deny why he ended up in the prison; he openly admits he was sentenced for life for murder. However, Jack is worried that everyone else judges him based only on this aspect of his existence, and the filming becomes a way to emphasise the other parts of his life – being a family man, a contributing member of the prison community and a World War II veteran. These aspects of his identity are not only about what he has done, but what kind of relationships are important to Jack. Hunter argues that legacies always rely on relationships that create, transform and pass legacies on. These relationships include both interpersonal and socially interconnected relationships, such as culture and society as a whole (Hunter 2008, 318). Similarly, Jack seeks redemption in all these relationships, with his family, community and society.

The most personal level of these redemptive relationships involves his family. Jack sees himself as a family man, even if he has made troubling choices due to mental health issues (post-traumatic stress disorder following military service

during World War II) and alcohol abuse. Throughout the filming, Jack proclaims how proud he is of his son and grandchildren, and the prison hospice enables him to spend time with his family. Unlike other wards, the hospice ward allows flexible visiting rights, which makes it possible for Jack to rebuild a strong and affective connection with his family. At the end, Jack's son is sitting by his deathbed. The filmmaker captures the son's caresses when Jack takes his lasts breaths (Figure 7.1). The opportunity to witness this affective connection creates a transformative experience: the viewer sees Jack through a humanising lens. Despite his mistakes, Jack is loved and worth caring for. The family's affection and ability to forgive help the viewer to support Jack's desire to redeem his morality and honour.

The second level of Jack's redemptive relationships takes place within the prison community. He has lived and worked within that community for decades, and during his last weeks the viewer sees glimpses of what personal growth has taken place during these years. First, Jack seeks comfort and atonement in Christianity. The religious rituals, particularly the holy communion, symbolise his repentance and atonement. Second, Jack is recorded in the prison infirmary, where he had been placed for twelve years after a heart attack in his early seventies, and later, in hospice, being taken care of by black volunteers. These prisoners sit by Jack's bed and share moments of laughter and sorrow. Jack's son reads this as a sign of personal growth because Jack used to be a racist and a supporter of segregation. Jack has had a change of heart and has abandoned his racial prejudices, which marks his seeking

Figure 7.1 Jack on his deathbed, fragile, comforted by his family in *Prison Terminal* (Barens 2013).

redemption and also makes him more relatable in the contemporary viewer's eyes.

The third level of Jack's redemptive relationships is society and his role in it. Because of his conviction, Jack feels like an outcast, yet his past as a soldier brings him comfort. On several occasions, he returns to the memories of serving in the war and being a celebrated war hero who protected his country, its people, values and lifestyle. These memories and experiences are not tainted by his later actions, and he hopes to build his public legacy on being a veteran. He hopes to be transferred to a soldiers' home for hospice care, but when the decisions are delayed, he settles into the prison hospice and feels comforted by the thought of getting to be buried in the military section of the cemetery. The final resting place in the war veterans' section serves as his release from prison and a restoration of his role as a respected veteran and citizen in the eyes of society. The film ends with Jack's coffin being transported outside the prison walls. He is free, and he has reconciled his identity for himself, for his family, for his prison mates, but also for the wider public, who can now evaluate how he will be remembered.

For Jack, participation in the documentary project is an attempt to create a redeeming legacy. While he cannot determine how others will define his legacy, he can attempt to shape it. William Breitbart (2016) calls this process the 'legacy that one lives', witnessing oneself, observing and appraising potential legacies and searching for significance. In this process, knowledge of forthcoming death gives meaning and context to the search of significance and evaluating which values one wants to transfer to those witnessing and to the following generations. Similarly, Naomi Richards (2013, 197) argues that the experience of witnessing such storytelling processes becomes meaningful because both the subject and the viewer know that the subject is going to die, which guides attention to the passage of time. Legacy documentaries do not seek to freeze their subjects in the moments when they are alive and active, because the final evaluation of the meaningfulness of their lives can only be actualised after their death. Consequently, legacy documentaries include physical aspects of the dying process in on-screen images, they dedicate space and time to increasing bodily fragility, and sometimes, as in the case of Jack, these films invite the viewer to the deathbed to witness the death of the subject. Jack's death serves as a point of reference, where the viewer has all the information about his actions, morals and values to decide whether they want to align themselves with Jack's desired mode of remembering.

Jack's death in incarceration can appear as an ultimate punishment for his crimes, but his death also adds a humanising element to his legacy. Film director Edgar Barens (2019) recognised that the prisoners had hurt other people, but he wanted to show that at the end of the day, prisoners are just people, and death carries emotional affects to humanise the prison population:

> The biggest common denominator for everybody is to see somebody to die. And I know it sounds kind of ruthless, but I thought that if they [the viewers] see someone die, it might remind them of their father, or grandfather, who they saw pass away. It also brings it all down to the same level. And also I was able to show the prisoner's family who loves this person despite their flaws, show the path to a grieving process as the person dies. That can be so powerful. (Barens 2019)

As this quote illustrates, Barens builds a story where the viewer can learn to understand, if not necessarily accept, Jack's experiences, and to recognise his desire and need for redemption of his soul, but also his legacy. Scott Combs's (2006, 281) argument that 'cinema wants to solve the basic problem of the loneliness of death, to mediate the event of someone's death so that it communicates to the outside world' adds an interesting perspective to Jack's story. The film project ensures that Jack is not dying alone, but his death is witnessed by his family, the prison community and the public. Consequently, being by his deathbed, whether physically or through the camera, becomes both a sad and a cathartic moment. The redemptive legacy provides comfort for Jack and for the viewer because his hospice death was better than the alternative – dying alone in his cell – and because his attempts to become a man worthy of his war hero status provide a kind of happy ending for the film. Jack does not die as a murderer, but as a family man and a veteran, gaining his freedom in a publicly acceptable way. The morality of these actions allows the viewer to mourn the loss of his life.

Filmmaker and Ethical Commitment to Legacy-Building

While end-of-life documentary films enable legacy-building for the filmed subjects, these legacies are also mediated and built through filmmaking. A successfully documented legacy requires the interpretative and productive work of the filmmaker. José van Dijck argues that mediated autobiographical memories represent both personal and cultural practices. In other words, narrated memories are related to a person's manifested perceptions and experiences, but at the same time, cultural practices, such as documentary traditions, influence the forms of expression and guide what is remembered and how (van Dijck 2004). In *Helen's Story*, too, the filming process enables a young mother to leave a tangible legacy for her children, to self-reflect on her emotions, particularly the shifting moods between hope for recovery and desperation over progressing cancer, and to explore her roots for deepened self-knowledge. However, these personal legacy processes are filtered through documentary practices. Co-director Paul Davidson says that first they recorded the events as sensitively as possible, but the story was only created after all the footage

had been filmed. And, while the documentary is not a scripted art form, 'it still has to have almost the classic movie structure, with the opening, the tension point, and resolution of tension, unexpected things and the viewer wondering what was going to happen' (Davidson and Gibb 2020). Consequently, the film narration includes various creative aspects, music, illustrations, interviews and moments without Helen's presence.

The film opens with a funeral scene of Helen's coffin being carried. From these images, the film cuts to family photos where Helen poses with her children, while the opening lines of the song 'The Biggest Love' play on the background, lyrics describing a beginning of a journey and life that is waiting to be lived (Davidson 1990). For Paul Davidson and Barbara Gibb (2020), the directors, the decision to open with the funeral scene and to reveal the sad ending of the story, was a difficult one. The opening removes any possibility of recovery from cancer. The certainty of death changes how the viewer engages with Helen: the viewer pays attention to how Helen deals with her mortality and what kind of legacy she leaves behind.

From this starting point, the film narration builds two legacies. The documentary portrays Helen's dealing with terminal illness and receiving help from hospice care. Helen describes the day of receiving her diagnosis as a moment when 'everything just changed, that day'. The knowledge that she might die earlier than expected launches a difficult and emotional journey. At first, Helen processes her progressing illness through a metaphor of 'fighting' the cancer, a rather typical even if a problematic cultural expression in illness stories (de Muijnck 2019, 48; Rimmon-Kenan 2002, 14). Later, however, the battle transforms into finding 'inner strength' to die a dignified death. Along the way, hospice staff, palliative treatments and activities such as art therapy help her. The film uses Helen's experiences to show the benefits of hospice care and the emotional advantages of learning to accept one's death. Thus, the film's public legacy that Helen helps to build is to claim that good end-of-life care can lead to dignified dying.

Still, the film becomes as much a story of Helen's reconnecting with her roots and creating her personal legacy based on her heritage. Helen has been adopted by a Caucasian family, but the forthcoming death prompts her to learn the whole story. She tracks down her Caucasian biological mother, and later, the Māori family from her biological father's side. The terminal illness encourages her to search for her long-lost relatives and Māori roots, and enables her to embrace Māori cultural practices. From the perspective of the filmmakers, this level of personal legacy added positive interest to the story. Davidson and Gibb (2020) argue that one person's journey towards death might not be a good story by itself, so while they did not initiate the search for lost family connections, this storyline gave added tension and structure to the narrative. The search for family roots drives the scenes, and Helen's desire

to reconciliate her family backgrounds – that of her European-descended, Christian family and her aboriginal, Māori family – becomes a part of her life. To search for closure increases the story's appeal because it provides an option for a 'happy ending'. Naomi Richards, who followed the filmmakers' work with hospice patients to create films, also noted that the filmmakers typically built a redemptive narrative into the stories. In other words, they presented a problem that could be resolved during the film, and while the main character's illness or dying process could not be resolved, the viewer could be offered at least one kind of catharsis during the film (Richards 2013, 196).

For Davidson and Gibb (2020), emphasising the 'happy' elements and resolution was a conscious decision. The filmmakers wanted to balance the tragedy of Helen's story with other emotions, such as joy from successful medical interventions, the happiness that a baby brings to the family, the love for the family members and the reconciliation with the lost relatives. Gibb argues that they paced the film so that the emotional arcs encourage the viewer to stay with the film:

> If you just watch all the sad parts, you would lose your audience, because it would just be too much. So, I think, it is also about hospice journey, that despite all, you get better and you get back into your life and then you get sicker and there is this other world of death. […] Especially visually we were aware not just keeping the mood in balance, but also physically we had some really beautiful up-moments as well which were, I think, well paced. Just to keep the whole thing uplifted. Letting people know that it is okay to have pure joy. (Davidson and Gibb 2020)

This emotional structure that eases the viewer's entry into the story is highlighted in the culmination point of the documentary, where Helen successfully reconciles the two sides of her heritage – the white, Christian culture and the indigenous culture. Helen's story started from her need to renegotiate her identity, to embrace her Māori roots and to gain knowledge of where she comes from and to whom she is linked. However, during the film this personal identity project turns to a quest for legacy, a desire to achieve something that lasts beyond her death. In other words, Helen desires to create a lasting connection between the families so that when she is gone, the connection would endure for her children, and she would become an important link in the ancestral line.

To achieve this, Helen organises a farewell party for all sides of her family. Bringing everybody together, she mends different parts of her identity, but in addition, she uses this event to build a legacy. The party is organised in a *marae*, a Māori cultural space for social gatherings. Food and other proceedings are prepared by using Māori rituals and traditions. The social gathering celebrates Helen while she is still alive, but Helen uses the event to introduce

people to each other and make them a family. Helen's own assessment, 'I think I achieved it,' is supported by her brother's comments on Helen's efforts: 'She is the connection that brought us together.' Helen dies shortly after, which highlights the reconciliation story's cathartic function. The viewer is comforted that Helen managed to achieve something lasting, a legacy to reach beyond her death. This achievement makes both her life and death meaningful.

Coming back to the filmmakers' decision to open the film with the funeral scene, we can see that their structural decision anticipates death and marks the forthcoming death as something that gives meaning to the story that is about to unfold. In addition, it includes elements of both tragic and happy endings. The funeral signifies the devastating death of Helen, but it also includes images of reconciled family connections. When Helen's coffin is brought out from a Catholic church, it is welcomed by a group of people performing *haka*, an expressive cultural art by Māori. In Māori culture, *haka*, a posture dance performed together with chanted or shouted song, has various expressive functions, including farewelling and mourning the deceased family members. It can be interpreted as a ritualised sign of respect (Matthews 2004). The multicultural coexistence of Christian and Māori cultures is testimony to Helen's legacy, a healer of family connections. Thus, the opening already implies that the film is both an end-of-life story and a reconciliation story about legacy.

From the ethical perspective, Davidson and Gibb were committed to giving space to Helen's personal legacy. At the same time, they wanted to ease the viewers into the topic gently, so that they would not be shocked but could share emotionally a positive connection with Helen (Davidson and Gibb 2020). This editing process compares to Asbjørn Grønstad's reading of Michael Haneke's fiction film *Amour* (2012), where the husband takes care of his wife after her stroke. Similarly to legacy documentaries, Grønstad argues that anticipation of death gives form to the film because care and illness bring mortality into the lived life. Still, instead of focusing merely on subjective experience, the film highlights the ethics of love and responsibility. Grønstad sees the husband's role as an ethical commitment to the situation. Here, ethics is not a social practice at first glance. It negotiates a relationship, when the forthcoming death gives 'the responsibility of legacy upon the one who is left behind' (Grønstad 2016, 139–43, quote from 139). While Grønstad's interpretation is based on a relationship between two fictitious characters in a drama, it paints a picture where ethics can be seen as a social practice. Those who remain after the subject's death have responsibility to care, not only physically and emotionally but also in terms of understanding the legacy. Similar expectations can be extended to filming end-of-life stories. The filmmakers have a responsibility to care, and one form of this care is to mediate the legacy desired by the dying subject. Thus, respect for legacy-building is an ethical act of social practice, in which the filmmakers commit to telling a dying subject's story.

Viewer and Validation of Legacy

All films expect a viewer, legacy films even more so. One's legacy and symbolic immortality remains inactivated if others do not acknowledge and validate it. Thus, in end-of-life documentaries, it is the viewer's responsibility to determine how the filmed subjects are remembered. Richards (2013, 191) suggests that hospice film projects where the patients build legacies need to be recognised by the audiences, because otherwise their thoughts and words would lack the empowering aspect of leaving something behind. This recognition requires ethical engagement from the viewer. The engagement and remembering are ethical actions that validate the experiences of the dying and confirm their continuing social influence after death. In a way, the expectation and promise of the viewer's gaze comforts the dying subjects, who can be assured of a posthumous legacy.

The nature of the validation, however, is in the hands of the viewer. Instead of leaning on the theoretical viewer to study the validation of legacy, reception study deepens the understanding of how the actual audiences react to end-of-life documentaries. I organised twelve focus-group interviews with forty-eight participants recruited from universities, universities of applied sciences, and cancer and grief support groups in Finland. The participants watched a Finnish documentary, *Marika's Passing* (Wallenius 2021a), and then joined a group discussion to share their feelings (a detailed reception study results, Hakola 2022; 2023). The documentary follows a middle-aged woman's last months in hospice care. Marika has terminal cancer, but she is determined to live fully until the end while preparing for her forthcoming death. Marika displays a self-made death doll that she wants to be buried with, a nature-inspired coffin gown, and she also invites the filmmaker (and consequently, the viewer) to test her custom-made green coffin. Open discussions about death and dying, a positive attitude and individual choices for funeral rituals serve as the film's and her legacy: the documentary celebrates the opportunities and freedom to plan a unique death and funeral in Finnish culture where death rituals have been quite homogeneous. The film's director Peter Wallenius (2021b) interpreted Marika's willingness to participate in the documentary as her wanting to help others in a similar situation, living with a terminal illness. Crucially, the film also enabled Marika to build a legacy and continue to live through the film.

The group interview participants reacted positively to Marika's preparations for death. They felt that she had enough time from the diagnosis to death to process and accept the situation. She had both the time and the courage to discuss death with her family and friends. Her willingness to participate in the planning of her own funeral was mostly seen in a positive light. The unique and individual choices that differ from the 'typical' Finnish funeral rituals were

welcomed as liberating and empowering. Many participants felt that Marika showed that it was possible to renew 'old' and 'dusty' traditions, and they were inspired by the promise that they would not have to follow a certain model for death rituals, either. These rituals can be customised to fit personal styles and desires. Marika's choices were, however, questioned by some participants. These resistant voices felt that the funeral and the mourning rituals are for those who are left behind, which is why they should have more say on them. For many, a traditional funeral might be more comforting than a bespoke occasion of unique choices. Despite the perspective on the topic, the viewers recognised that the filmmaker and Marika wanted to use the film to open a discussion on the changing roles of end-of-life and death rituals in Finland. The viewers thereby validated the accepting and open approach to planning one's end of life as the film's sociocultural legacy.

However, the discussion on death rituals was not the main topic that the viewers wanted to tackle. Most attention was given to Marika's relationship with her spouse. At the beginning of the film, Marika's spouse is standing by her, and they do all kinds of fun things together – enjoy a music festival and try to make the best out of the last months together. When Marika's physical and psychological condition weakens, the relationship faces challenges. The moment of their ultimate conflict is not recorded on camera, but both parties comment on it in interviews. Marika explains being hurt by the spouse's comment in an argument: 'Your death is the least of my worries at the moment.' She feels she is not getting support and care at home and therefore distances herself from the situation and seeks solace by switching from home care to in-house hospice care. The spouse regrets his ill-chosen words, maintains that Marika refuses to accept his apologies and is hurt to be shunned. This sets up a conflict, an issue that screams for reconciliation and for a 'happy ending' of the documentary.

In the same manner as in *Prison Terminal* and *Helen's Story*, Marika's personal relationships add drama and build narrative tension. Wallenius recognises that the marital rift lent the film a captivating storyline, which also served the director's interests to show what people talk about before death. The relationship conflict stressed that life, with its twists and turns, continues until the end. Relationships continue to evolve and change, and life does not freeze. Therefore, a complicated relationship allowed Wallenius to build an honest portrayal of being human until the end, with all kinds of emotions, not only smiles, good humour and positive feelings (Wallenius 2021b).

The decision to let things play out lasts until the end. Unlike in the other documentaries discussed in this chapter, there is no happy ending, no reconciliation between spouses. The film's last scenes are dedicated to Marika's death. She is lying on her hospice bed, breathing heavily and looking fragile. She is surrounded by people. Her brother, a priest, gives her the final blessing. While

the camera, and the viewer, are invited to this intimate moment of goodbyes, the spouse is missing. The camera pans away from the scene, and the filmmaker cuts to an interview with the spouse. In a close-up, the spouse looks directly at the camera. He shares the unpleasant feeling of being cut off and not being able to say goodbye. The interview ends when he tells that one Monday morning the call came that Marika had died, and a lone tear rolls down his cheek revealing the raw emotion of distress. In the next images, Marika's hair is gently combed, her corpse is covered up and she is transported out of the hospice. The final scene is pre-recorded with Marika, who in her coffin gown and with her death doll strolls through a forest, peaceful, as if on another plane. These scenes implicate that while Marika is at peace, the spouse is left with the burden of unresolved issues.

The viewers had strong reactions to the representation of this course of events. Many blamed the spouse and said that he should have supported Marika; he should have kept his inconsiderate comments to himself. They found that the end of life was such a short time that one should be able to stay supportive. Others allocated some of the blame towards Marika, too. They felt that she should have been forgiving and understanding in an emotionally difficult situation. Regardless of who the viewers chose to side with, they shared their disappointment of the continued conflict. The unresolved situation became traumatic not only for the filmed subjects but also for the viewers. The viewers kept hoping for reconciliation, which would have given them closure and a 'happy' ending for a life story, a respectful legacy.

The anticipation of reconciliation originated from social expectations of a desirable relationship and death. The demand for strong and durable relationships at difficult times is comforting, because the representations of such relationships promise that the viewers are entitled to expect the same from their own relationships – unwavering support in sickness and in health. The demand to settle arguments before death would promise a 'good death'. One of the respondents argued that 'peace and harmony with everything and everyone is part of the good death experience', and continues that 'from this perspective, her [Marika's] death was not a good death. After all, this was a beloved person, and then there was this disturbing issue.' A public promise, or claim, that people can put an end to disagreements would strengthen the expectations that we can hope for the same at the end of life.

Thus, when Marika refuses to aim for reconciliation, the documentary can turn into a 'demoralising experience', as Jennifer Malkowski contends. In this experience, the narrative appears to lose its sense of purpose and goal, particularly in a culture that values individual accomplishment (Malkowski 2017, 84). Marika's refusal to adapt to the story of reconciliation is not only an individual 'failure' to create a positive legacy but also a refusal to build a safe, cathartic experience for the viewer. Some of the participants of the group

interviews openly acknowledged their desire for cathartic closure, and they, interestingly, demanded that the filmmaker should assume responsibility for the narrated conflict. They were aware that the filmmaker could have chosen to edit the conflict out of the film and include only the scenes where Marika and the others were happy, accepting of death and joyfully preparing for it. This, they thought, could have been a perfect way to reduce death anxiety. Instead, they thought that the film had conflicting elements. While its accepting attitude towards death was comforting and 'rosy', the troubled marital relationship made the film 'brutally' realistic. These discussions showed that the viewers were conscious of the filmmaker's power and role in legacy-building.

These discussions unfold the normative expectations of a positive legacy, which would involve order, closure and non-conflicting emotions. However, narrative studies show that this may be an unreasonable and unrealistic expectation in a life story. This field of study has slowly grown out of the idealisation of control, coherence and continuance that would increase well-being and provide emotional closure (Frank 1993). The field has started to embrace realities where narrative identities are formulated in complex personal and social lives marked with discontinuities, chaos and fragmented experiences (McAdams 2011, 102–4; Rimmon-Kenan 2002, 21–3). A similar discussion could also benefit the field of legacy-building. In the reception of *Marika's Passing*, a small proportion of the viewers tried to convince others of the benefits of narrating a conflict story. For them, the documentary served as a public acknowledgement that the end of life does not turn into a polished version of life. A life-threatening illness raises complicated emotional reactions. The end of life can cause anxiety, distress, aggressiveness and guilt in the dying people and their relatives. These realistic experiences should be given time and space. Thus, *Marika's Passing* builds an honest and realistic approach to the topic and provides peer support and possibilities for self-reflection of their own experiences. The representation of difficult emotions can add to the trustworthiness of the documentary and the ethical practices of filmmaking.

Consequently, the study of the audience's validation of the film's claim and legacy reveals that the ethical expectations of the documentary can vary within the reception. For those who desired a comforting and positive approach to an end-of-life story, a redemptive or reconciliating narrative would have appeared as the desirable narrative mode. It would also have been an ethical choice to respect the privacy of the subjects' intimate issues, and to lessen the death anxiety of the viewer. However, for those preferring honest access to difficult emotions and a troubled relationship, the frank perspective served as an ethical choice in the filmmaking. This choice affords public space to discuss the various sides of end-of-life experiences, and as such, it could at least validate the lived experiences of many, instead of building idealistic and rosy images of end of life. And at the very least, the film encouraged its viewers to reflect on

what they saw in relation to their own values and experiences, which is one potential of the ethical cinematic space.

Conclusion

In legacy documentaries, death is made meaningful by defining the unique aspects of a person's life and by imagining how their social influence continues after death. The documentaries give meaning to the subjects' end-of-life experiences as they are turned into messengers of what dying is as an experience. Also, these films create space for personal life stories that build personal legacies of the subjects' actions, values and beliefs. By creating affective relationships with the dying subjects, the documentaries portray them as worth remembering, and the viewer has an essential function as a witness of their legacy, and consequently, an authoriser of symbolic immortality. Brenda Longfellow (2013) points out that these kinds of memorialisation practices are always political: what or who is publicly memorialised and how they are memorialised are signs of what issues and what kinds of people are considered important for public discussions and the collective memory. While the prominent figures of history and celebrities have had several documentaries dedicated to them, such end-of-life documentaries as *Helen's Story*, *The Prison Terminal* and *Marika's Passing* represent a significant turn in that memorialisation and symbolic immortality have become available to 'normal' people as well. The digitalisation of culture, including filmmaking, has provided opportunities and a desire to document various lives for future generations (Aceti 2015; Walter 2015; Jacobsen 2017). The boundaries between the personal and the public have shifted to give room to various legacies.

The legacy-building practices also vary within end-of-life documentaries. *Prison Terminal* and *Helen's Story* use redemptive and reconciliation narratives to emphasise the morality of the filmed subjects, which builds a positive understanding of legacy. In these documentaries, death provides a tragic ending to personal experiences, yet the reconciliation of identity and relationships before death provides a partial happy ending to the stories. In these cases, the moments of the subjects' deaths are culmination points of their legacies. All is well in their worlds, and they can leave at peace, knowing that they left something meaningful behind. In contrast, *Marika's Passing* paints a more complex image. The viewer can recognise the beauty of Marika's open, and even accepting, approach to death, yet the troubled relationship with the spouse casts a shadow over this legacy.

These narrative endings are always constructed. With different editing choices, *Marika's Passing* could have constructed a similar positive story of legacy-building as did *Prison Terminal* and *Helen's Story*. In Helen's case, the filmmakers noticed that the family dynamics changed after her death, and

reconciliation between the families was not as straightforward, easy or free from tensions as Helen imagined (Davidson and Gibb 2020). In Jack's case, the filmmaker says, the cemetery refused to let his body be buried in the war veterans' section because a new law stipulated that any capital crime leads to withholding all veteran benefits. This was devastating for Jack's family, but the filmmaker was glad that Jack did not know about this decision that refused him his honourable return to society (Barens 2019). Thus, while the legacy of the dying people kept evolving after their deaths, these two documentaries chose to portray a positive validation of their legacies.

These various choices on how to proceed on legacy-building are tied to the intentions for the film's public legacy. By giving the viewer the possibility of verifying the benefits of prison hospice programmes through building an allegiance with Jack's experiences, director Edgar Barens ensured that *Prison Terminal* could build public acceptance towards hospice projects. Similarly, by reconciliating two cultural traditions – European-descended culture and Māori culture – filmmakers Paul Davidson and Barbara Gibb showed that hospice care could benefit all citizens regardless of their background. In turn, *Marika's Passing* used complicated relationships to publicly acknowledge and allow space for the complex emotions and restraints that the approaching death can bring onto the surface, even if some viewers find these emotions difficult to encounter. Thus, the legacies of the dying people in end-of-life documentaries are always created in the triangle of their own legacy-building, the filmmakers' goals and the viewer's validation.

References

Aceti, Lanfranco. 2015. 'Eternally Present and Eternally Absent: The Cultural Politics of a Thanatophobic Internet and Its Visual Representations of Artificial Existences'. *Mortality* 20 (4): 319–33. https://doi.org/10.1080/13576275.2015.1085297.

Barens, Edgar. 2013. *Prison Terminal: The Last Days of Private Jack Hall*. Documentary. HBO.

———. 2019. Personal interview by Outi Hakola.

Bennett, Jeffrey, and Jenny Huberman. 2015. 'From Monuments to Megapixels: Death, Memory, and Symbolic Immortality in the Contemporary United States'. *Anthropological Theory* 15 (3): 338–57. https://doi.org/10.1177/1463499615575943.

Boles, Jessika C., and Maile T. Jones. 2021. 'Legacy Perceptions and Interventions for Adults and Children Receiving Palliative Care: A Systematic Review'. *Palliative Medicine* 35 (3): 529–51. https://doi.org/10.1177/0269216321989565.

Breitbart, William. 2016. 'Legacy in Palliative Care: Legacy That Is Lived'. *Palliative & Supportive Care* 14 (5): 453–4. https://doi.org/10.1017/S1478951516000705.

Brylla, Catalin, and Mette Kramer. 2018. 'A Pragmatic Framework for the Cognitive Study of Documentary'. *Projections* 12 (2): 159–80. https://doi.org/10.3167/proj.2018.120216.

Carter, Rodney G. S. 2007. 'Photography and Personal Mythology'. *Queen's Quarterly*, January. https://www.academia.edu/6726476/Photography_and_Personal_Mythology. Last accessed 11 April 2022.

Combs, Scott. 2006. 'Final Touches: Registering Death in American Cinema'. PhD dissertation, Berkeley: University of California.
Davidson, Paul. 1990. 'The Biggest Love'. Song.
Davidson, Paul, and Barbara Gibb. 2016. *Helen's Story*. Documentary. Bytesize Productions.
———. 2020. Personal interview by Outi Hakola.
Dijck, José van. 2004. 'Mediated Memories: Personal Cultural Memory as Object of Cultural Analysis'. *Continuum* 18 (2): 261–77. https://doi.org/10.1080/10304310420002150 40.
Fioretti, Chiara, Ketti Mazzocco, Silvia Riva, Serena Oliveri, Marianna Masiero, and Gabriella Pravettoni. 2016. 'Research Studies on Patients' Illness Experience Using the Narrative Medicine Approach: A Systematic Review'. *BMJ Open* 6 (7): e011220. https://doi.org/10.1136/bmjopen-2016-011220.
Frank, Arthur W. 1993. 'The Rhetoric of Self-Change: Illness Experience as Narrative'. *The Sociological Quarterly* 34 (1): 39–52.
Grønstad, Asbjørn. 2016. *Film and the Ethical Imagination*. London: Palgrave Macmillan. https://doi.org/10.1057/978-1-137-58374-1_10.
Hakola, Outi. 2021. 'Ethical Reflections on Filming Death in End-of-Life Documentaries'. *Mortality*, June, 1–16. https://doi.org/10.1080/13576275.2021.1946025.
———. 2022. 'Kuolemisen Mediatisaatio: Yleisön Odotukset Marikan Kuolema - Dokumenttielokuvalta'. *Media & Viestintä* 45 (4): 1–21. https://doi.org/10.23983/mv.125624.
———. 2023. 'Mielikuvat Suomalaisesta Saattohoidosta Marikan Kuolema - Dokumenttielokuvan Vastaanotossa'. *Lähikuva – Audiovisuaalisen Kulttuurin Tieteellinen Julkaisu* 36 (1): 25–44. https://doi.org/10.23994/lk.128785.
Haneke, Michael. 2012. *Amour*. Les Films du Losange.
Hunter, Elizabeth G. 2008. 'Beyond Death: Inheriting the Past and Giving to the Future, Transmitting the Legacy of One's Self'. *OMEGA – Journal of Death and Dying* 56 (4): 313–29. https://doi.org/10.2190/OM.56.4.a.
Jacobsen, Michael Hviid. 2017. *Postmortal Society: Towards a Sociology of Immortality*. Studies in Death, Materiality and the Origin of Time. London; New York: Routledge.
Lifton, Robert Jay, and Eric Olson. 1974. *Living and Dying*. London: Wildwood House.
Longfellow, Brenda. 2013. 'The Practice of Memory and the Politics of Memorialization: Denis Villeneuve's *Polytechnique*'. *Canadian Journal of Film Studies* 22 (1): 86–106. https://doi.org/10.3138/cjfs.22.1.86.
McAdams, Dan P. 2011. 'Narrative Identity'. In *Handbook of Identity Theory and Research*, edited by Seth J. Schwartz, Koen Luyckx, and Vivian L. Vignoles, 99–115. New York: Springer. https://doi.org/10.1007/978-1-4419-7988-9_5.
Malkowski, Jennifer. 2017. *Dying in Full Detail: Mortality and Digital Documentary*. Durham, NC; London: Duke University Press. https://doi.org/10.1215/9780822373414.
Matthews, Nathan. 2004. 'The Physicality of Māori Message Transmission – "Ko Te Tinana, He Waka Tuku Kōrero"'. *Junctures: The Journal for Thematic Dialogue*, no. 3. https://junctures.org/index.php/junctures/article/view/168. Last accessed 16 October 2022.
Muijnck, Deborah de. 2019. '"When Breath Becomes Air": Constructing Stable Narrative Identity during Terminal Illness'. *Colloquy*, December. https://search.informit.org/doi/abs/10.3316/informit.853861612257940.
Richards, Naomi. 2013. 'Rosetta Life: Using Film to Create "Bearable Fictions" of People's Experiences of Life-Limiting Illness'. In *Envisaging Death: Visual Culture*

and Dying, edited by Michele Aaron, 190–205. Newcastle upon Tyne: Cambridge Scholars Publishing.
Ricœur, Paul. 1980. 'Narrative Time'. *Critical Inquiry* 7 (1): 169–90.
———. 1992. *Oneself as Another*. Chicago, IL: University of Chicago Press.
Rimmon-Kenan, Shlomith. 2002. 'The Story of "I": Illness and Narrative Identity'. *Narrative* 10 (1): 9–27.
Smith, Murray. 2022. *Engaging Characters: Fiction, Emotion, and the Cinema*. First published 1995. New York: Oxford University Press.
Wallenius, Peter. 2021a. *Marika's Passing* (*Marikan kuolema*). Documentary. Yleisradio.
———. 2021b. Personal interview by Outi Hakola.
Walter, Tony. 2015. 'Communication Media and the Dead: From the Stone Age to Facebook'. *Mortality* 20 (3): 215–32. https://doi.org/10.1080/13576275.2014.993598.
Werth, Brenda. 2013. 'A Malvinas Veteran Onstage: From Intimate Testimony to Public Memorialization'. *South Central Review* 30 (3): 83–100.

8. PHYSICAL DOCUMENTARIES

Experiencing the Process of Dying

In 1976, American filmmaker Michael Roemer released *Dying*, a documentary of three terminally ill people facing their deaths. Filmed over a period of two years, the documentary creates intimate portraits of cancer patients' everyday lives. 'I have no fear of death,' says Sally, one of the three, in an opening scene framed by soothing classical music and a long, quiet gaze out of the hospital window. By repeating pacifying and understanding moments like this, the film seeks to alleviate the anguish of death. The approach mostly resonated with audiences, yet film critic Stefan Fleischer voiced concern that the film 'rings false':

> The main problem and limitation of the film *Dying* is, oddly, its sense of tact and good taste in dealing with a taboo subject. Perhaps these defects are, in a sense, obligatory: Roemer knew he had an important subject, he knew he wanted it on national television. He therefore produced a film which 'fit' the demands of the marketplace. In so doing he made a beautiful film on an ugly subject, whereas it could be that what is needed is an ugly film. (Fleischer 1978, 30)

Fleischer blames the film for making dying a mental rather than a physical process. Similar criticism can be levelled at most twenty-first-century end-of-life documentaries, where death anxiety is met with comforting views of how to manage and improve one's mental capability to deal with death (see, for

example, Chapters 4 and 7). Some filmmakers have confronted the assumption head-on that avoiding the physical aspects of dying would serve to alleviate fear. Many end-of-life filmmakers fall back on metaphors and symbolism to soften the potentially upsetting nature of non-fictional death, but Steven Eastwood, director of *ISLAND* (2017), argues that this is not the only ethically acceptable approach to the topic:

> I wanted to enable the viewer to feel comfortable sharing in the event of the end of a life, without the protection of veils and metaphor. There is no sun going down. There are no polite symbols to reassure the audience that everything is going to be okay. That is what metaphor does; it suggests meaning, a purpose for everything, but moreover, that someone else is managing your experience. […] We can trust ourselves to encounter dying directly, outside of the filters of metaphor and euphemistic language. (Eastwood 2018)

In this chapter, I analyse physical end-of-life documentaries that lay bare the increasing fragility, loss of independence and consciousness, and often, the moment of death. Filmed in the palliative care unit at Toronto Grace Health Centre, the Canadian documentary *Dying at Grace* (King 2003) witnesses the dying processes of five terminally ill patients: Carmela, Joyce, Richard, Lloyd and Eda. The Australian *Love in Our Own Time* (Murray and Hetherton 2011) compares the moments of birth and death through seven families, of whom John, Jutta, Doug and Noelene are living their last weeks at Calvary Hospital. *The Perfect Circle* (Tosi 2014) follows two hospice patients, Ivano and Meris, in the hills of Reggio Emilia, Northern Italy, and the British documentary *ISLAND* (Eastwood 2017) captures four dying people, Jamie, Mary, Alan and Roy, at Mountbatten Hospice on the Isle of Wight. All four films relate the physicality of dying to ideas of communicating to the viewer the experience of dying.

Ethics of Observational Documentaries

Dying at Grace opens to a white text on a black screen: 'This film is about the experience of dying' (King 2003). In the absence of titles, voiceover or other explanatory elements, this proclamation guides the viewing experience. In the audio commentary of the film's DVD release, director Allan King explains: instead of wanting to portray hospice care or meanings of death, the film set out to explore 'what it feels like to die, what it looks like to die' (King, Walker, and Hector 2008). Steven Eastwood (2018), similarly, wanted to 'show' people what death and dying is. These quotes highlight how physically oriented end-of-life documentaries focus on showing rather than explaining death.

The four documentaries follow the everyday lives of dying people at hospices and palliative care centres. The scenes observe mundane moments and avoid interviews or voiceovers. Also, the narration is about the here and now – and about the future, the prospect of death – instead of seeking to understand the subjects' past lives. The viewer does not hear detailed personal stories of who these people are, where they come from and what they have done before ending up in a hospice. For both Allan King (King, Walker, and Hector 2008) and Steven Eastwood (2018) this was a conscious choice: as the backstories would not have been about the present experience of dying, they would have focused the viewer's attention on information on the subjects. The choice to see present events and feelings as the most meaningful in the face of death guides the viewer's attention to the increasing loss of physical capability, a dimension of dying that can be observed without knowing the dying subjects.

Another way that physicality is given priority over the mental aspects of dying is the role of mundane conversations about weather, food, sports and so on. The subjects are not asked to tell their life stories to the camera or give meanings to impending death. These topics are referred to only if they come up in daily discussions with other characters. Claudia Tosi, the director of *The Perfect Circle*, was asked by the hospice to avoid intrusive questions, thus she chose to 'let the conversation go where it naturally goes'. She continues:

> if the filmmaker would ask them to talk about what they think about death, they probably would, but what would be the point in that? Why does this dying person need to talk about illness and death, why would that be more important than what for example Messi thinks about death? After all, he is going to die as well. (Tosi 2018)

Thus, instead of finding meanings for death and dying in the ways in which the subjects talk about the issue, the meanings come from showing their everyday experiences before death.

In their desire to show, physical documentaries follow the practices of observational documentaries, which prefer not to create a driving argument. They favour showing emotional experiences over telling or explaining them, and as such they position the viewer to witness the lived life (Nash 2011, 225, 229; Nichols 2017, 132–7). Allan King finds that the experience is the key in observational 'actuality drama': 'filming people as they experience their life and to do so in such a way that they will share their lives with the camera and the filmmakers. So that we can actually experience what they experience as they experience it' (King, Walker, and Hector 2008). Michele Aaron (2016, 206), accordingly, interprets the opening line of *Dying at Grace* as inviting the viewer to share or co-experience the experience of dying.

In turn, Madeleine Hetherton, co-director of *Love in Our Own Time*, argues that the observational mode helped them stay clear of expert voices explaining the subjects' experience and guiding the experience of the viewer. Rather, the unstable viewpoints allow viewers to project their own experiences to what they witness (Hetherton 2020). The opportunity to intimately witness the subjects' lived life without guidance and definite conclusions encourages the viewer to engage with the filmed subjects and the story in an active and critical manner (MacDougall 2018, 4, 8; Nash 2011, 225–9). Thus, the observational mode is as much about the viewer's experience as it is about the experience of the subject.

The observational traditions, where events apparently roll in their own space and rhythm, may comfort the viewer who can experience first-hand interaction with the subjects. Yet, in the context of observational documentaries, the risks in power relations between the filmmaker and the subject as well as between the subject and the viewer are at the very core of ethical discussions (Nichols 2017, 132–7; Nash 2011, 225, 228). Most end-of-life filmmakers are sensitive to issues of trust, consent and the inclusion of the subjects' viewpoints in the filming process (West 2018; Hakola 2021), so here I will focus on how the ethical portrayal of others is managed in the film style and its invitation for the viewer to witness death and dying. The prominent role of the viewer as an observer has raised ethical worries that observational documentaries might increase the distance between us and the other and diminish the affective connection needed for ethical space. Vivian Sobchack (1984, 299), for example, argues that the observational approach may give ethical consent to witness real-life deaths, but the witnessing often turns to impersonally and technically watching someone else die. Susan Sontag (2004, 34), similarly, questions whether a lack of background information might turn viewers into voyeurs and the dying people into distant others. In line with these concerns, several scholars have recognised an emotional and affective engagement with the subjects as a starting point for an ethical viewing experience (Gibson 2011, 924–5; Elsner 2020, 148–9). Physical documentaries create affective intimacy through tangible vulnerability of the dying subjects instead of using personalised stories to create engagement.

This opposes physical documentaries to the mainstream neoliberal imagery which celebrates unique personhood and customised death. The promise of individual exceptionalism in death allows the viewers to distance themselves from the dying subject – viewers can be assured that their future death will be different (Aaron 2020, 89; Malkowski 2017, 77–9). In contrast, in physical documentaries, the processes of dying have similar patterns and a lack of background stories guides towards universality. For Tom Murray (2020), the interconnectedness was the starting point in *Love in Our Own Time*, which proceeded to see death as something we all go through, 'an intrinsic

part of life'. Similarly, Elsner (2020, 158) regards non-individualised deaths as ways of showing interconnectedness both between human beings and with nature. Death is a part of life in human lives, but in other life cycles as well.

Jennifer Malkowski (2017, 77–9, 105, 107) argues that non-individuality is one of the reasons why physical end-of-life films, which do not shy away from showing deathbed scenes, are so rare in the documentary field: repetitive scenes of the final stages of dying deny viewers a safe distance. Not getting to know the person too well can guide the viewer to engage with the physical process of dying as a human experience. Aaron claims that we need this kind of alternative imagery that reveals the physical vulnerability of the dying process (and the complexity of relationships, see Chapter 11) without compromises. In other words, when viewing someone else's suffering, an open and full confrontation with human vulnerability could create ethical space (Aaron 2020, 100–1). The observational approach to the physical dying process, thus, has ethical potential to use embodied engagement with the other in a way that invites the viewer to face their own mortality.

Physical Transformation, Time and Embodied Engagement

Embodied engagement in physical end-of-life documentaries is built through cinematic means other than life stories or individual dying processes. In physical and observational documentaries, it is the intimate aesthetics, embodiments and materiality that produce the transformative power of images. Observational documentaries create intimacy by using such cinematic techniques and filming practices as small, portable cameras and small film crews that allow close relationships with the subjects in intimate spaces and help to engender a trusting relationship (Nash 2011, 225–9). All the while, during the long filming processes, encounters between the filmmakers and the subjects evolve, grow deeper and are heightened, which translates into the viewer's experience as well.

End-of-life documentaries build an intimate and a material connection between the viewer and the subject through transformation. For example, *Dying at Grace* introduces Eda to the viewer in scenes where she wanders into other patients' rooms for gossip. She is active, talkative and even hopeful that there might be some good news on cancer treatments. At the end of the film, Eda is on her deathbed, unconscious, unable to communicate and breathing heavily. Throughout these documentaries, the viewer witnesses the declining health of the subjects, how they turn from social and talkative individuals to bodies quietly bound to their beds. It is these corporeal aspects that invite the viewer to affectively respond to the film and co-share the embodied transformation before death.

In ethical discussions, time and transformation have been in a key role in understanding documentary cinema's relationship to death. Vivian Sobchack argues that documentary cinema is not able to semiotically represent the existential shift from being to non-being (the moment of death). Instead, end-of-life representations are limited to representing the gradual dying processes and death's becoming 'ritually formalized as a moral consideration of the mortal conditions of the body, of the fragility of life' (Sobchack 1984, 297–9, quote from 299). This framing marks the process of dying as less interesting than the exact moment of death, yet many are afraid of the process of dying itself, physical decline, pain and symptoms, and loss of independence (Missler et al. 2011; Lehto and Stein 2009), which should make the portrayals of processes significant for end-of-life documentaries – precisely because of the agonising slowness of these processes. Perhaps documentary cinema can expose the 'processual, drawn-out quality of dying' (Elsner 2020, 9), enable the experience where 'mortality spills over into lived life' (Grønstad 2016, 141) or create 'transitional space' where the material presence of a dying person guides us to engage with mortality (E. Wilson 2012, 47–51).

To make death visible, cinematic expressions have tended to focus on violent death. Violence has the ability to lend movement, colour, sound and actors to the process of dying and visually transform a living body to a non-being abruptly and in a sudden transformation (Sobchack 1984, 289–90; Grønstad 2016, 9–10, 238–40). While violence can visualise the process of dying, other cinematic modes, such as slow processes of non-violent dying, could provide ethical engagement. Aaron (2016, 216) notes that natural and unexceptional deaths that are void of the historical and political traumas often connected to violent deaths (such as war deaths), can turn the gaze at death itself, not at other issues surrounding it. In this way, everyday deaths can become revolutionary forms of resistance in attempting to engage us with unavoidable mortality. Furthermore, Grønstad (2016, 119–25) argues that while the twenty-first century is marked by a constant flow of moving images that appear and disappear at a breathtaking pace, the slowness of images is almost a negation of mainstream cinema. Transformations which take their time demand the viewer's commitment; they create intimacy and offer an alternative to action-oriented society. As such, they create ethical potential for engagement with others.

Gradual transformations to death allow us to witness what the process of dying looks like. The slow progress also prepares us for the moment of death. Without backstories, the subjects' increasing vulnerability is turned to intimacy and engagement by the time we have spent together. Carl Plantinga (1999, 239), for example, links engagement and temporality because humane connection always occurs in time. Thus, time with the subjects strengthens the connection between the viewer and the dying person. Editor Nick Hector, for

example, explains that the slow rhythm of *Dying at Grace* serves to increase intimacy. The viewer slowly gets to know the patients. At the beginning of the film, when the first subject, Carmela, dies, she is the one the viewer knows the least about. At the end of the film, the last subject to die – Eda – is the one that the viewer knows best (King, Walker, and Hector 2008). Eda's death becomes the film's culmination point on the emotional and embodied level. The viewer cares about her death. While this increased intimacy creates visual rhythm, our familiarity with the characters depends not on how well we know their personal stories, but on how we live along with them through their last months, weeks and days.

The slowness of dying is also visible in the slowness of the images. The observational camera is not in a hurry to cut away from the subjects. Instead, the viewer sees them shuffling with wheeled walkers or in wheelchairs, staring out of the windows, being quietly present in moments without action or dialogue. In *Love in Our Own Time*, for example, one of the dying characters, Noelene, is often filmed on a balcony having a smoke or staring outside. During the film, there is no significant action connected to Noelene, but she is filmed having breakfast or going to the bathroom. These moments are typical of observational cinema, which in its attempts to capture the events and moments as and when they happen prefers long takes that minimise fragmentation of images and create temporal unity (Nash 2011, 228; MacDougall 2018).

Slow and concentrated intimacy is why Grønstad argues that slow cinema has ethical potential. Indeed, when duration and presence become central cinematic content, the slow aesthetics, such as composition stillness, action unfolding in real time, dedramatisation of events, careful framing and long takes visualise the passing of time. The viewer can experience the flow of time on an embodied and material level. Grønstad notes that 'duration as a temporal mode and experiential frame' provides possibility for such ethical acts as 'recognition, reflection, imagination, and empathy' (Grønstad 2016, 75–6, 81, 103, 122, 127, quote from 121). The slowness of images that is dedicated to bodily transformations invites the viewer's engagement in ways that highlight both the subject's and the viewer's presence and awareness of loss of time and opportunities.

In *The Perfect Circle*, declining physical health is pictured through repeated scenes of Ivano, one of the main subjects, going to the bathroom. In the first of these scenes, Ivano struggles to get out of bed, and after succeeding, leans on his wheeled walker, and the camera follows Ivano as he makes his way to the bathroom door. The wife rolls her eyes at Ivano's independence and desire to show that he is still able and capable. Later, a similar scene is repeated. This time, Ivano needs help to get out of the bed and is assisted by the wife to walk to the bathroom. The last time the scene is repeated, Ivano is looking thin and fragile. He would like to go the bathroom, but the wife tells him that he is no

longer capable of doing this. Disappointed, Ivano leans against the pillows. The signs of declining health are concrete and material, and Ivano's sense of loss of independence is palpable, an experience that the viewer can recognise and connect with. A scene like this reveals our common anxieties, which invites the viewer's responsibility over the material vulnerability of the filmed subject.

The transformation from a living and acting body to an inanimate corpse is often slow and agonising. For Steven Eastwood (2018), *ISLAND* 'is about time and the body, and the gradual shift from personhood into something else'; for Madeleine Hetherton (2010), deaths in *Love in Our Own Time* are slow transformations where you watch something disappear; and for Allan King (King, Walker, and Hector 2008), film editing needs to recognise dying as a process that takes time. This is where the film finds its rhythm – in the slow progress. The passing of time in fact became a theme in *Dying at Grace* because the film crew wanted to give the viewer a sense of unfolding days and what almost translated into boredom while waiting for death (King, Walker, and Hector 2008).

A similar sense of experiencing time has been recognised in studies of hospice and palliative care. Patients' lived experiences and bodily transformation make clock time less important than inner time, creating a sense of how time feels in relation to their bodily functions (Pasveer 2019; Ellingsen et al. 2013; Lindqvist et al. 2008). Time is sensed in terms of 'before and after I was able to go to the bathroom by myself', for example. This embodied time has been vividly described as 'it is not the clock that stops ticking, but the heart that stops beating, when lifetime is ended' (Ellingsen et al. 2013, 170). Thus, time and transformation are not merely a question of observing the slow progress of dying, but they offer an invitation to co-experience the embodied time of the dying person – the increasing loss of bodily functions, hanging on to the disappearing life, and anticipation of death. This also uncovers the ethical potential of slowing down both embodied and cinematic time in physical end-of-life documentaries. Slowness enables an intimate relationship between the viewer and the subject, a shared experience of temporality, and thus an increased demand for responsibility that encourages the viewer to recognise the mortality of the other person and of oneself.

Transforming with Affection-Images

In the discussion of transformation, time and intimacy, Gilles Deleuze's 'becoming', or transforming with images, manifests through movement-images. These are images of perception, images of affection and images of action, which together describe the embodied and affective transformation of the images and the viewer. The perception-image refers to shots which orient the viewer (and the subject) to the world, the location, the moment and various actors in

that scene. Affection-images, which are key to ethical engagement, reveal the transformation from one state of experience to another. Affection-images show how the world and the situation affect the filmed subject (and the viewer) and reveal one's capability to react to events. Affection-images prioritise emotions, desires, hopes and needs, and are often close-ups, which engage the viewer to recognise and connect with the subjects' experiences and feelings. The action-image, then, can follow the affection-image, as the subjects' reaction helps the viewer to understand why they act the way they do (Deleuze 1986). While the viewers witness the slow transformation of dying through filmed subjects, their engagement with this transformation emerges from changing (intimate) images.

Among the opening scenes of *Dying at Grace* is a montage of healthcare staff taking care of the patients. Instead of filming the nurses, the image focuses on the dying people. Cinematographer Peter Walker says that this was a conscious, even if at times challenging, decision. It would have been cinematically typical to film the action of the nurses giving care, but it would have created distance between the viewer and the subject. Thus, it is not the camera focus on acts of care, but the patient's face that remains the focal point of these moments (King, Walker, and Hector 2008). These affection-images, or close-ups, as West (2018, 1489) reminds us, highlight corporeal intimacy and serve as 'a technique for connection and understanding'. In Carmela's case, the nurse is included in some of the shots, but the camera keeps focusing on Carmela's face, often in close-up. This asks the viewer to pay attention to Carmela's expressions, reactions and emotions. Carmela quietly follows the treatment, her expression meditative, sad, even absent.

In the Introduction (Chapter 1), I brought up Levinas's concern that we rarely see the other because we tend to explain the world through our own experiences. For Levinas, the face of the other suggests a way out of self-centredness and creates potential for an ethical encounter. The face and the facial expressions go beyond closed and linguistic meanings, making it conceivable that sameness and otherness can be recognised at the same time. The moving image, particularly, may elicit subtle movement of expressions, which encourages the viewer to react to the face before conscious and informational meaning-making adds sociocultural attitudes to the mix. Face-to-face encounters, Levinas suggests, thus create potential for ethical intimacy, to seeing the other and experiencing responsibility toward them (Levinas 2011).

For purposes of intimacy, physical end-of-life documentaries often linger on the face. Claudia Tosi, for example, emphasises the meaning of close-ups in *The Perfect Circle*. They are seen as tools to bring the subjects' expressions and reactions (affection-images) to the fore. Close-ups are there to create a strong emotional bond with and an emotional reaction from the viewer. Instead of using establishment shots (perception-images), Tosi prefers cutting straight

to the emotion, to the point where 'nothing breaks the emotion' (Tosi 2018). In *The Perfect Circle*, the affective power of close-ups is visible in the scene of Meris's birthday party. Her family and friends are visiting at the hospice. There are presents, laughter and happiness (or at least, displayed happiness). In the midst of it all, the camera focuses on Meris's face and its obvious rawness and sadness (Figure 8.1).

Claudia Tosi remembers this scene for disclosing the inner and emotional conflicts of a dying person:

> If Meris would have been happy all the time at that party, it would only have been a description of the party. We don't know what she is thinking, but at that moment she was not in the room. This was not possible in every scene, but that is what I try to do, to find an element that builds the conflict – a visual or sound element in the scene as a focus point. By a close-up I can tell a story about her state of mind that compares to the happiness of everyone else. (Tosi 2018)

This affection-image gives the viewer a sense of intimacy, a recognition of raw feelings and a connection to the realisation of loss of opportunity to celebrate further birthdays. The affection-image transforms birthday celebrations into a melancholic anticipation of death.

In *Dying at Grace*, the closer we get to death, the more close-up images the narration uses. At the beginning of each of their stories, the dying subjects are filmed in their surroundings, walking the hospital corridors, going to their

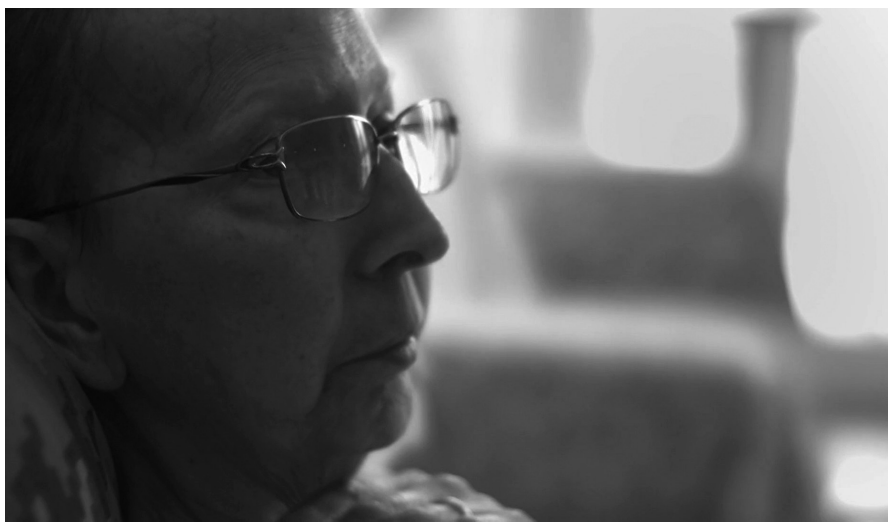

Figure 8.1 Close-up of Meris at the birthday party in *The Perfect Circle* (Tosi 2014).

treatments. When their situation changes, the camera not only stays by their bedside, but opts for medium shots and medium close-ups. By the deathbed scenes, the camera is focused on their faces, often in close-ups. This spatial change increases the intimacy: the viewer is brought closer to the emotions, but also closer to the embodied loss. In these moments, Aaron (2016, 212) argues, the viewer can recognise the 'cessation of cognition', where the dying person 'ceases to be able to engage with others, when communication, awareness, agency and even subjectivity recede'. Aaron refers to Joyce from *Dying at Grace* as an example. At one point, the previously active Joyce turns quiet and starts to stare emptily into nothing. Aaron sees this as an example of 'raw life', where subjectivity has lessened, but is not missing. These moments enable the viewer to see and feel something otherwise unknown, something existentially raw which demands responsibility from the viewer. As such, these moments make the approaching death visible without dehumanising the subject or distancing the viewer (Aaron 2016, 212–13; 2014, 174–6). Indeed, together with the (slowly) transforming framings and affective images, the viewer becomes entwined with the character, highlighting the intimacy of the situation. The only affective contact points that the viewer has by this stage are fragile bodies and faces. This connection serves as the core of an ethical experience of what dying might feel like, or at least what it looks like.

Filming Moment of Death

Physical end-of-life documentaries commonly show the moment of death. Whereas many other end-of-life filmmakers prefer to keep the moment of death private (Merikanto 2018; Luostarinen 2020; Davidson and Gibb 2020; T. Wilson 2019; Wallenius 2021), Claudia Tosi was the only director of the analysed physical documentaries whose deathbed scene finishes before the moment of death. Because death's timing is unpredictable, Tosi was filming elsewhere at Ivano's final moment:

> Ivano was shot until after an hour until he died. He was asking me to be there and wanting me to be there. And I looked at the cinematographer and said, we'll just do what he wants. And this is when he was shooting me and Carla touching his hands. He really wanted to be touched, in that very moment, so we did it. It was a warm, not a cold moment. (Tosi 2018)

Ivano is lying in his bed, tired, weak and drawn. He lifts a finger, asking the people in the room to come closer. The camera also moves closer to his bedside. We can see the filmmaker and Ivano's wife holding Ivano's hand. The image cuts to look out of the window, into pouring rain. At the same time, the sound of difficult breathing continues in the background, until it

stops, and only the rain goes on before quiet instrumental music begins. The scene, particularly the end of it, is a reminder of the film's opening with images of rain, sounds of breathing in the background, deep sighs and wind. The difference is that death is no longer a prospect waiting to happen, it has arrived, but throughout this journey, a sense of intimacy has increased. By the end, the viewer is close to Ivano, sees him looking fragile and thin on his deathbed, and hears his laboured breathing. While the sight of his thin arms can make the viewer flinch, the difficult breathing embodies the fragility of the situation. Compared to the vivid person in the earlier scenes, the loss of being is painfully visible and felt. Touching and caressing do add to the intimacy, but they also are about affect, not action. As such, the deathbed scenes are intensely affective.

The deathbed scenes are the emotional and narrative culmination of physical end-of-life films. Steven Eastwood (2018) describes the seven-minute take of Alan's death as one that 'made the film', and Allan King (King, Walker, and Hector 2008) sees the almost three-minute-long sequence of Eda's death, the subject whom the viewer knows best, as the crux of the whole documentary, something everyone has been waiting for. These filmmakers identify the moment of death as the most central aspect of their documentaries, whereas scholarly debate on filming these liminal moments has been rather critical.

In 1949, André Bazin wrote an essay 'Death Every Afternoon', where he argues that because death is a unique moment, the last moment of an individual's experienced time and life, cinema – as based on repetition and replay – would only violate moral and metaphysical aspects of death. Bazin compares the filming of death to missing the 'real presence', an image that is 'emptied of its psychological reality, a body without a soul'. As such, documenting the moment of death would be obscene, a perversion, as it can never relay the unique essence of that moment for the viewer (Bazin 2003).

In 1984, phenomenologist Vivian Sobchack returned to the topic with a similar argument that cinema could not reach the multiplicity of death as an experience: death 'is always original, unconventional, and shocking, its event always simultaneously representing both the process of sign production and the end of representation'. Thus, according to Sobchack, the non-being that death ultimately is remains unrepresented. Any documentary representation can be purely technical, not a lived-body experience (Sobchack 1984, 283–7, quote from 286).

In 2017, Jennifer Malkowski continued the discussion of death's assumed unrepresentability from a technological perspective. For Malkowski, cinematic technology can never 'meaningfully' represent a liminal event such as death. The camera can only pursue external signs. As death is an internal experience, documentary cinema is 'unable to show death "in full detail", as it remains beyond representation even amid image technologies that can record

it more fully than ever' (Malkowski 2017, 7). These arguments, expanding from one decade to another, focus on the moment of death and the documentary camera's challenges to communicate the totality of that experience. Problematically, they also seem to expect first-person consciousness as the criterion for cinematic representation, a demand that is not used in other contexts of embodied or affective experiences. For example, could we ever experience love or pain as someone else does?

I argue that if we approach these filmed moments of death from the vantage point of their potential for ethical intimacy, even death can be seen as a co-sharable experience. Viewers are not expected, or even desired, to experience death in ways that would make this experience their own, but through embodied connection they can feel the loss related to the ultimate transformation from being to non-being. These filmed moments bring the undeniability of death into the sphere of experience, and it would be peculiar to claim that this should or could not be done due to existential concerns. Instead, the desire to reach towards non-being, to explore the fragile moments between animate and inanimate, or life and death, can make us ask existential questions and can make us aware of our mortality.

Stillness and Death

Still, as Malkowski suggests, death can be problematic to cinema that builds on movement. Corpses, by definition, are still. Thus, cinema often adds movement to dead bodies that are carried and pushed around (Malkowski 2017, 42). Physical documentaries also utilise this, as is evident in the opening of *Dying at Grace* with a scene of a corpse being taken to a morgue. However, in the deathbed scenes, the movement is minimal, thus forcing the viewer to pay special attention to it. The camera is in an enclosed space. The filmmakers use long takes. The focus is on dying people in their beds. The close-ups and medium close-ups create a sense of intimacy that leaves no escape route where the viewers could distance themselves from the image. The absence of a non-diegetic soundtrack increases the sense of presence and realism.

For example, Eda's death in *Dying at Grace* lasts almost three minutes, while a hand-held camera keeps shooting a close-up of her face. The death scene is primed with earlier shots of nurses visiting Eda's bedside to check on her condition. The final scene, however, starts without any further orientation for the viewer, without a perception-image. Instead, the camera dives straight into the affection-image, emphasising the viewer's connection to Eda. Her eyes are half-closed, every breath difficult, gasping for air with difficult swallows, almost as if it were an unwanted action. Breathing is the main audible and visible element in the scene, where it causes movement of cheeks and a slight bobbing of the head. Haptic connection to the affection-image invites viewers

to become bodily aware of their own breathing, its rhythm and its automated nature. This consciousness makes the viewers pay attention to breathing's necessity for the lived experience and continuation of inner, embodied time (Hakola 2022).

During the scene, the silence-interspersed pauses between breaths increase until there is no single laborious gasp left. It allows the viewer to focus on Eda's vulnerable transformation from a state of aliveness to state of being dead. The film ends with this image, a close-up of inanimate Eda lying on her deathbed. In other words, there is no follow-up or action-image that would give the viewer an outlet or an example of how to properly react to the situation. Only reference to the continuation of universal time is the change from post-mortem silence to the beeping sounds of the medical equipment that gradually become audible. They remind us that life continues, leaving the viewer solely responsible for reacting to Eda's death. Thus, the scene does not assume that the viewer transforms with the image to the experience of being dead, but to the state of being responsible for their watching someone dying, for caring about her death.

For Sobchack, these kinds of deliberate decisions to focus on the deathbed scenes give the viewer an ethical permission to be present in the situation. The long take and carefully framed image promise that the camera is not accidentally in the room; the dying subject has given permission to the filmmaker, and by extension to the viewer, to witness. This 'humane stare', to use Sobchack's words, appeals to the viewer's responsibility and respect towards the other, and prompts an 'ethical stance toward the event of death s/he witnesses' (Sobchack 1984, 294, 297).

Regardless of the ethical permission to witness, both Sobchack and Malkowski argue that these scenes fail to create a connection with the viewer that is required for an ethical experience. For Sobchack, connection is impossible with an unintentional dying subject, much less with an inanimate corpse, which is a sign of 'dead', instead of 'death' as an event. Thus, when the dying person has lost subjectivity, the potential for embodied connection disappears. Sobchack takes the lack of reciprocity of the gaze, where the dying person is no longer able to return the viewer's gaze and demand responsibility for viewing, as a sign of lost subjectivity (Sobchack 1984, 287–90). However, while the gaze is an important aspect of cinematic connection, the ethical implications of reciprocity can be questioned. Aaron (2016, 214), for example, contends that even if the scene of Eda's death includes 'no-return' of the gaze, the director does 'not depend upon this humane looking back for his ethical approach'. Director King argues, indeed, that Eda's earlier consent provides reciprocity and that her continued blank stare should be interpreted as a gift from a courageous person, who gives the viewer her last breath (King, Walker, and Hector 2008).

According to Aaron, a feeling towards the other continues, even without a reciprocal gaze and even after the other is no longer present. The continued feeling creates a possibility for something mystical and unknowable to be made, at least on some level, knowable (Aaron 2016, 216). Aaron bases this interpretation on Anat Pick's (2011, 157) concept of the blank gaze, which describes moments where 'the subject looks into the camera, but the gaze bypasses us without endorsing the communicability between spectator and subject'. Whereas for Sobchack this lack of reciprocity is both an ethical and a metaphysical challenge, Pick approaches the issue from the perspective of recognition of vulnerability. When the viewer realises that the subject is unable to look back and recognise the presence of the viewer, viewers face their own responsibility over the situation. Pick proposes that ethics might even start with the blank gaze: 'For what is ethics if not my seeing without being seen – my unrequited attention?' (Pick 2011, 158–9) Aaron, in turn, connects this unrequited attention to 'raw life', which enables ethical encounter precisely because this unfamiliar connection decentres the viewer. The lack of confirmation of consent forces the viewer to be solely responsible for making sure that the engagement remains ethical (Aaron 2020, 89–90). The deathbed scenes suggest that potential feeling of discomfort can engage ethical feeling and thinking. The viewer must take responsibility for their choice to either engage in affective and embodied witnessing or detach themselves from the situation.

Malkowski approaches the challenges related to the moment of death from the realisation that cinematic technology cannot pinpoint the exact moment of death, the ultimate transformation from being to non-being. No matter whether the film rolls on time, or these images are slowed down to single photographs, the inner experience of dying cannot be made visible (Malkowski 2017, 28, 71). Further, the desire to pinpoint the exact moment is rather banal. Even in medical science, the exact moment, and even the very definition of death, are fluid and fleeting. Death can be declared only after it has happened. In end-of-life documentaries, we see healthcare staff checking the patients' breathing and pulse to ascertain the status of their being dead. Why should cinema, then, be able to capture the moment that can be fleeting to people present in the situation? Perhaps the viewer's intimate connection to the dying subject, carried through with long and intimate takes is meaningful because of the slow transformation to non-being, instead of a sharp moment of transition.

Both transformation and continued connection with the dying become visible in Alan's death scene in *ISLAND*. To capture the moment, Eastwood filmed for forty-eight hours straight after Alan lost consciousness. When Alan died, Eastwood was asleep, and the camera was the only witness of the moment. For Eastwood, this vigilantly and independently recording camera meant the filmmaker's role in (re)framing the moment was diminished, and as such, the

moment becomes shared between the viewer and the subject: 'You are used as a viewer to have the filmmaker as the chaperon, as a guide. When I am sleeping, it is just you and Alan, so in many ways the viewer gets to experience what I don't' (Eastwood 2018). While the placing of the camera relies on the filmmakers' intentions, it lessens their role when the scene momentarily prioritises the embodied link between the camera, the viewer and the subject (Nichols 1991, 86). In a close-up, similarly to Eda's case, the camera captures Alan inhaling and gasping, placing the viewer as an embodied witness. The affection-image serves also as a reminder of Levinas's ideas that face of the other can invite the viewer to abandon self-centredness in the situation. Through close connection, the viewer experiences how Alan frequently seems to take his last breath before gasping for more air. His moment of death can only be identified after it has already occurred since the viewer continues to vigilantly watch for the next breath. This makes Alan's embodied time fluid, and by extension the viewer's co-experience becomes fluid as well.

After Alan's last breath, when the gasps stop, only silence and non-movement remain, until a nurse enters the room and notes that Alan has died. There is no rush to cut away from the scene, the viewer's presence in the situation continues, as if having a personal wake for Alan. Indeed, because slow images contradict the cinematic preference for movement, these are powerful moments (Remes 2012, 259–61), and in deathbed scenes the slowness highlights the importance of the moment, the death of a person, and the ethical connection with that person.

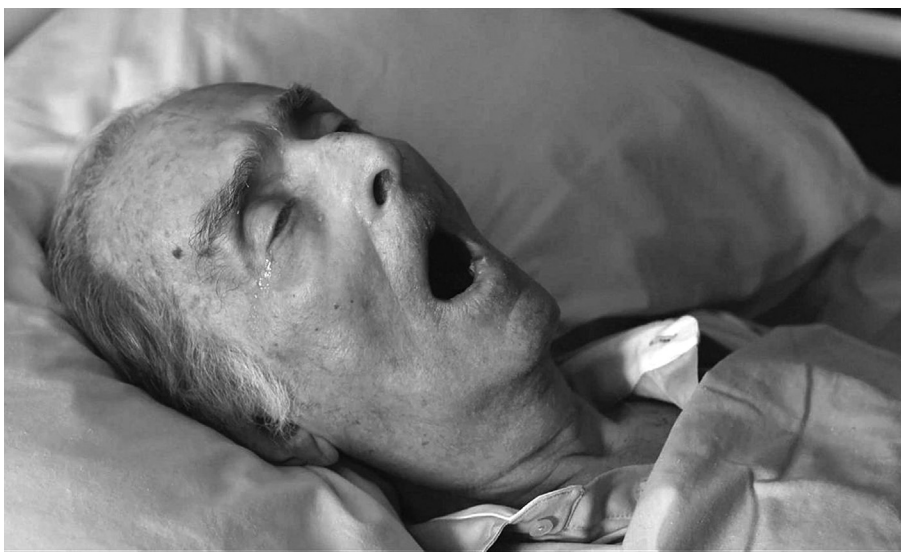

Figure 8.2 Death scene of Alan in *ISLAND* (Eastwood 2017).

This combination of silence and non-movement also marks a transformation in embodied time. The film does not end when both sound and movement cease. Even if nothing changes, the frames keep moving, making a spectacle out of stillness. As Justin Remes (2012, 263–7) argues, when nothing apparently happens in the image, the viewer witnesses as time goes by, and this witnessing creates a constantly evolving experience. In Alan's case, the long take by the deathbed invites embodied connection through his recognisable vulnerability, and after his death, the continued use of stasis helps the viewers to recognise the loss. When they realise that Alan has died, the viewers also recognise the continuation of life around them. Universal time moves on, the viewer's embodied time moves on, and when the nurse enters the room and action restarts, the focus readjusts to those who remain and to the viewer, who all react to Alan's death.

The differences between still and moving images have promoted philosophical discussions about images' relationship with temporality and mortality. The traditional view emphasises still and inanimate images as reminders of death and loss, whereas the movement serves as a sign of life (e.g. Bazin 1960; Sontag 2001). In Alan's scene, the continued statis breaks down this separation because the scene is not about the frozen frame but about nonaction within the moving frames, which communicates the loss, not life. From another perspective, Laura Mulvey also considers the classical division artificial. For her, the potential to freeze any moving image into a still, to break down the movement, reveals that the sense of the subject's presence is always an illusion (Mulvey 2006, 21–31). As such, any moving image carries mortality with it, only serving an illusion of aliveness.

In a way, Alan's death scene seems to fit this description of mortality – after all, this scene is directly about death and dying. However, death is not the only reference within these images. Affection-images of Alan are not merely about his experience, but in a Deleuzian manner, they become part of the viewer's experience as well. The viewer's affect happens in presence. Thus, the moment is a sign of loss and mortality, but also a lived experience of these. This recalls Emma Wilson's (2012, 5–6, quote from 6) argument that instead of communicating death, images become traces 'of embodied experience, of sensuousness, of engagement with the world, up to and beyond death'. In other words, it is the viewer's affective and embodied transformation with images that creates continuing connection. The combination of this idea of the viewer's continuing transformation and the viewer's sole responsibility without reciprocal connection in the situation reveals how the viewer may engage with the dying subjects not only up to their deaths but beyond them as well.

When the subjects die, the films do not necessarily finish. Instead, these documentaries often direct the viewer's experience of death and dying towards an experience of loss through other people, family and friends. In *Love in Our*

Own Time, Jutta's death is the culmination of the film. This documentary likens death to birth: co-director Tom Murray argues that both life and death are miraculous.

> The language that we have around these experiences speaks to the miraculousness of life seemingly coming from nothing … and in some ways in death. We have a living human being and then when they die, they very quickly transform into something else. You can almost immediately see that their life force is gone. So, in the sense that in both birth and death there is a transition between being and non-being there seemed a kind of similarity between the two, and I wanted to deal with that. (Murray 2020)

Jutta's death heightens this connection by deviating from the typical filming practices of deathbed scenes. The scene is a montage of two women in labour and Jutta on her deathbed. The sounds of birthing women's loud breathing are edited to echo Jutta's death rattle, and from the sound of the new mothers crying with happiness, the film shifts to the sounds of desperate crying and images of Jutta's family crying around her deathbed. In the case of *Love in Our Own Time*, the comparison between the defining moments of birth and death reflects the cyclical pattern of life. References to death as a part of life and nature are a part of other physical documentaries as well, which is seen in the references to water in *The Perfect Circle*, for example. While the argument of the naturality of death is used to highlight its inevitability, it does not aim to take away the sense of loss. Instead of focusing on the joy of new families, the camera returns to Jutta's deathbed and stays there with the grieving family. When Jutta's peaceful face is in close-up, the family remains present in the image and the viewer can see a hand caressing Jutta's face. The movement centres the experience on the family and their emotional reaction to loss. For co-director Madeleine Hetherton (2020), the family's reactions were more powerful than the actual death: 'It was a very unique kind of grief that we could watch him [the husband], and grieve with him.' Thus, the viewer's engagement is directed towards embodied grief, and this connection allows the viewer to co-experience loss, to take part in a shared moment and have a permission to mourn as well.

In the lonely deathbed scenes, such as those of Alan and Eda, the viewer becomes responsible for recognition of death and loss of a person, and the inclusion of other characters invites the viewer to connect with living subjects and shares their embodied affects. Cinematographer Peter Walker, for example, describes their experience of filming Lloyd's death in *Dying at Grace*. This death differs from Eda's yet has similar elements. The camera stays by

the deathbed, but this time, family members are present as well. Lloyd's difficult breathing fills the void, demanding attention while the family caresses him and gently whisper that it is okay to let go. The viewer's attention is thus divided between Lloyd's last breaths and family caresses. After death, the narrative focus re-centres on the family members' expressions of loss. The cinematographer remembers this moment as not only filming someone's death but as participating in the experience: 'I felt I was contributing, offering my support, being in the room. […] I was doing my job, […] allowing the audience to experience it as well' (King, Walker, and Hector 2008). Thus, the cinematographer felt that they were both co-sharing the situation with Lloyd and the family, but in addition, they mediated this potential for co-experience to the viewer as well.

Conclusion

Physical end-of-life documentaries and their deathbed scenes refuse to protect the viewer from emotionally, ethically and culturally difficult themes such as fragility of the dying and the moment of death. There is a sense of being present, which gives ethical permission to witness what the process of dying is as an experience. In addition to permission to witness, the viewer is given access to the increasing physical vulnerability of the filmed subjects, and this vulnerability calls for further responsibility – a demand to recognise the vulnerability in others and in ourselves. The responsible reaction, instead of objectification, is encouraged through cinematic means – slow aesthetics, emphasised intimacy and affection-images.

In turn, this responsible reaction to watch someone die can be seen as cinema's ethical potential: the viewers may open themselves towards the experiences of others, not by owning that experience, but by building an embodied and affective connection with the filmed subjects. This connection, I argue, reaches over the moment of death. The ambiguity in recognising the exact moment ensures fluidity for the embodied connection with the dying subject. Being present, then, sharing the fragility of the process of dying and the subtleness of transformations from being to non-being, can potentially transcend the limits of life and death. The viewer is allowed to co-experience the situation, if not death itself. In the observational documentaries that highlight the physical aspects of dying, the viewers are not asked to participate in meaning-making about death. Instead, they are expected to feel the emotions, affects and bodily experiences related to witnessing these processes. By giving the viewers access to the physical transformations of dying people, these documentaries may help the viewer to understand the process through experience and may transform the viewer as well.

References

Aaron, Michele. 2014. *Death and the Moving Image: Ideology, Iconography and I*. Edinburgh: Edinburgh University Press.

———. 2016. 'Watching Others Die: Dying at Grace (2003), Spectatorship, and the Ethics of Being Moved'. In *Malady and Mortality: Illness, Disease and Death in Literary and Visual Culture*, edited by Helen Thomas, 205–19. Newcastle upon Tyne: Cambridge Scholars Publishing.

———. 2020. 'Love's Revival: Film Practice and the Art of Dying'. *Film-Philosophy* 24 (2): 83–103. https://doi.org/10.3366/film.2020.0133.

Bazin, André. 1960. 'The Ontology of the Photographic Image'. Translated by Hugh Gray. *Film Quarterly* 13 (4): 4–9. https://doi.org/10.2307/1210183.

———. 2003. 'Death Every Afternoon'. In *Rites of Realism: Essays on Corporeal Cinema*, edited by Ivone Margulies, 27–31. New York: Duke University Press. https://doi.org/10.1515/9780822384618-003.

Davidson, Paul, and Barbara Gibb. 2020. Personal interview by Outi Hakola.

Deleuze, Gilles. 1986. *Cinema 1: The Movement-Image*. First published 1983. Minneapolis: University of Minnesota.

Eastwood, Steven. 2017. *ISLAND*. Documentary. Hakawati.

———. 2018. Personal interview by Outi Hakola.

Ellingsen, Sidsel, Åsa Roxberg, Kjell Kristoffersen, Jan Henrik Rosland, and Herdis Alvsvåg. 2013. 'Entering a World with No Future: A Phenomenological Study Describing the Embodied Experience of Time When Living with Severe Incurable Disease'. *Scandinavian Journal of Caring Sciences* 27 (1): 165–74. https://doi.org/10.1111/j.1471-6712.2012.01019.x.

Elsner, Anna Magdalena. 2020. 'Landscapes of Care and the Enchantment of Dying in Edwin Beeler's *Die Weisse Arche* (2016)'. *Studies in Documentary Film* 14 (2): 147–60. https://doi.org/10.1080/17503280.2020.1725994.

Fleischer, Stefan. 1978. 'Dying to Be on Television'. *Film Quarterly* 31 (4): 30–6. https://doi.org/10.2307/1211805.

Gibson, Margaret. 2011. 'Real-Life Death: Between Public and Private, Interior and Exterior, the Real and the Fictional'. *South Atlantic Quarterly* 110 (4): 917–32. https://doi.org/10.1215/00382876-1382321.

Grønstad, Asbjørn. 2016. *Film and the Ethical Imagination*. London: Palgrave Macmillan. https://doi.org/10.1057/978-1-137-58374-1_10.

Hakola, Outi. 2022. 'Breathing in Mortality: Demedicalization of Death in Documentary Films'. *Journal of Somaesthetics* 8 (1): 30–44.

Hetherton, Madeleine. 2020. Personal interview by Outi Hakola.

King, Allan. 2003. *Dying at Grace*. Documentary. Alan King Associates.

King, Allan, Peter Walker, and Nick Hector. 2008. *Audio Commentary. Dying at Grace. Dir. Allan King*. DVD. Alan King Associates.

Lehto, Rebecca Helen, and Karen Farchaus Stein. 2009. 'Death Anxiety: An Analysis of an Evolving Concept'. *Research and Theory for Nursing Practice* 23 (1): 23–41. https://doi.org/10.1891/1541-6577.23.1.23.

Levinas, Emmanuel. 2011. *Totality and Infinity: An Essay on Exteriority*. First published 1969. Pittsburgh, PA: Duquesne University Press.

Lindqvist, Olav, Birgit H. Rasmussen, Anders Widmark, and Lars-Christer Hydén. 2008. 'Time and Bodily Changes in Advanced Prostate Cancer: Talk About Time As Death Approaches'. *Journal of Pain and Symptom Management* 36 (6): 648–56. https://doi.org/10.1016/j.jpainsymman.2007.12.013.

Luostarinen, Kiti. 2020. Personal interview by Outi Hakola.

MacDougall, David. 2018. 'Observational Cinema'. In *The International Encyclopedia of Anthropology*, edited by Hilary Callan, 1–10. Oxford: John Wiley & Sons, Ltd. https://doi.org/10.1002/9781118924396.wbiea1535.
Malkowski, Jennifer. 2017. *Dying in Full Detail: Mortality and Digital Documentary*. Durham, NC; London: Duke University Press. https://doi.org/10.1215/9780822373414.
Merikanto, Tiina. 2018. Personal interview by Outi Hakola.
Missler, Marjolein, Margaret Stroebe, Lilian Geurtsen, Mirjam Mastenbroek, Sara Chmoun, and Karolijne van der Houwen. 2011. 'Exploring Death Anxiety among Elderly People: A Literature Review and Empirical Investigation'. *OMEGA – Journal of Death and Dying* 64 (4): 357–79. https://doi.org/10.2190/om.64.4.e.
Mulvey, Laura. 2006. *Death 24x a Second: Stillness and the Moving Image*. Repr. London: Reaktion Books.
Murray, Tom. 2020. Personal interview by Outi Hakola.
Murray, Tom, and Madeleine Hetherton. 2011. *Love in Our Own Time*. Documentary. Tarpaulin Productions.
Nash, Kate. 2011. 'Documentary-for-the-Other: Relationships, Ethics and (Observational) Documentary'. *Journal of Mass Media Ethics* 26 (3): 224–39. https://doi.org/10.1080/08900523.2011.581971.
Nichols, Bill. 1991. *Representing Reality: Issues and Concepts in Documentary*. Bloomington; Indianapolis: Indiana University Press.
———. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.
Pasveer, Bernike. 2019. 'Deadlines: Doing Times in (Dutch) Hospice'. *Mortality* 24 (3): 319–32. https://doi.org/10.1080/13576275.2018.1461817.
Pick, Anat. 2011. *Creaturely Poetics: Animality and Vulnerability in Literature and Film*. New York: Columbia University Press.
Plantinga, Carl. 1999. 'The Scene of Empathy and the Human Face in Film'. In *Passionate Views: Film, Cognition, and Emotion*, edited by Carl Plantinga and Greg M. Smith, 239–56. Baltimore, MD: Johns Hopkins University Press.
Remes, Justin. 2012. 'Motion(Less) Pictures: The Cinema of Stasis'. *The British Journal of Aesthetics* 52 (3): 257–70. https://doi.org/10.1093/aesthj/ays021.
Sobchack, Vivian. 1984. 'Inscribing Ethical Space: Ten Propositions on Death, Representation, and Documentary'. *Quarterly Review of Film Studies* 9 (4): 283–300. https://doi.org/10.1080/10509208409361220.
Sontag, Susan. 2001. *On Photography*. First published 1977. New York: Picador.
———. 2004. *Regarding the Pain of Others*. Paperback edition. First published 2003. New York: Picador.
Tosi, Claudia. 2014. *The Perfect Circle*. Documentary. Movimenta/MiaFilm/Cobos Film/Petra Pan Film Production.
———. 2018. Personal interview by Outi Hakola.
Wallenius, Peter. 2021. Personal interview by Outi Hakola.
West, Emily. 2018. 'Invitation to Witness: The Role of Subjects in Documentary Representations of the End of Life'. *International Journal of Communication* 12: 1481–500.
Wilson, Emma. 2012. *Love, Mortality and the Moving Image*. London: Palgrave Macmillan. https://doi.org/10.1057/9780230367708.
Wilson, Tim. 2019. Personal interview by Outi Hakola.

9. DIALOGICAL DOCUMENTARIES

Understanding Personal End-of-Life Choices

The Good Death (Krupa 2018a) begins with images of a garden and a house, while a woman's voice recites T. S. Eliot's poem 'A Song for Simeon'. A shot of the 72-year-old woman reading a book accompanies the last verses, which could have been written about her experience. In these verses, the poem's narrator talks about being tired with their life, and wanting to depart (Eliot 1928).

The poem sets the tone for Janette's plans to leave England for Switzerland, where non-profit organisations provide physician-assisted suicide for non-citizens like her whose own countries do not allow assisted dying. Janette has muscular dystrophy, a degenerative genetic disease her mother suffered from and which Janette has passed on to her own son. Janette recalls her mother spending thirty years just sitting in a chair, doing nothing. Janette does not want to experience a similar fate, which is hinted at in a scene of Janette struggling in an armchair. She tries different ways to pull herself up, but her movements are slow, unsure, and the progress is minimal at best. The chair symbolises the physical limitations of Janette's life, representing her struggle in everyday activities, but it is also a prison where one is forced to watch life happen to others.

In the director's statement on the film's homepage, Tomáš Krupa (2018b) commends Janette's open and intimate revelations of her physical and mental states. This, he says, makes *The Good Death* unique. Krupa continues the discussion on emotional intimacy in an interview for *Cineuropa*. He argues that emotional storytelling makes any film an instrument of change, not because

the film changes society, but because it can transform the thinking of those who can change society. His ideas highlight the ethical space's capacity for transformation: an open engagement with others can result in social change. Thus, with emotionally strong films, such as *The Good Death*, Krupa seeks to make important topics 'come to life on the screen' (*Cineuropa* 2020). Similarly, while *The Good Death* is related to legalisation debates over assisted dying, the film does not openly advocate for legalisation. Instead, it provides one personal story where the viewer is invited to understand (not necessarily to accept) why Janette desires to die.

The personal stories of assisted dying continue to discuss the (neoliberal) individualism that I introduced in the context of advocacy documentaries in Chapter 5. Assisted death is once again framed as an individual choice and responsibility, but from another perspective. Where advocacy documentaries discuss rational argumentation for or against assisted dying, personal stories focus on affective experiences. The Belgian documentary *Nathan – Free as a Bird* (Nollet 2014a), *The Good Death* (Krupa 2018a), a European co-production (Slovakia, Czech Republic, Austria, France), and two documentaries from the Netherlands, *A Dignified Death* (Venrooij 2018) and *Veda's Choice* (Villerius 2019) give access to the last months, weeks, days and hours of Nathan, Janette, Eelco and Veda. These documentaries create one personal portrait at a time and focus on their protagonist's emotional and mental experiences related to dying.

These films refuse to generalise their argumentation. Juan Fariña, Irene Cambra Badii and Ailen Provenza (2016) argue that films about assisted dying provide cases to study the moral, normative and ethical aspects of end-of-life choices. Addressing a 'singular realm', which they see as 'the true ethical dimension', these films transform ethics from normative principles to lived experiences. When ethical issues are represented through singularity, the varied personal contexts can be taken into account and understood in discussions about the moral and legal aspects of assisted dying (Fariña, Cambra Badii, and Provenza 2016, 296–304, quotes from 296). This reasoning chimes with Dan McAdams's (2011, 111) argument that western life narratives prioritise self-expression, individualism and the desire for 'uniqueness of the inner self'. In this chapter, I study how the singular approach asks the viewer to understand the personal stories and decisions of those wanting an assisted death. I approach the discussion from the perspective of hermeneutic phenomenology that aims to conceptualise how processes of understanding function. I suggest that in these documentaries, the dialogical approach to narration is used to increase understanding, and later, that this dialogical narrative mode asks the viewer to listen to what the subjects have to say. Consequently, I argue that in dialogical documentaries about assisted dying, the viewer's ethical relationship with the subjects is to be found in the ethics of listening.

Processes of Understanding

The hermeneutical tradition is described as an 'art of interpretation' (Abulad 2007, 11), but also as an 'art of understanding' (Kennedy Schmidt 2016, 1–6). Particularly, scholars, including me, who draw from the early-nineteenth-century writings of Friedrich Schleiermacher (1998) and the twentieth-century philosopher Hans-Georg Gadamer (1998) consider that understanding is the aim or the result of interpretative processes. The hermeneutical process, where meanings are interpreted and understanding emerges, also relates to the phenomenology of the film-viewing process. The viewer's embodied relationship with the film moves beyond perception and reaches towards meaning-making and understanding.

Hermeneutic phenomenology gives understanding a key role in lived experiences. It discusses how events and issues are experienced and interpreted by experiencers and those witnessing these experiences, and how understanding is built from such experiential structures (Wojnar and Swanson 2007, 174; Laverty 2003, 24). This definition allows room to recognise the layered structure of cinematic experiences. The main character often becomes the focal point for understanding: the person desiring to die aims to make others understand their decision. Often the other people in the documentaries exemplify these positions of trying to understand the wishes of the main character. This process adds a dialogical aspect to the film and also provides models for the viewer to witness. The viewer's understanding is thus constructed through various relationships with the filmed material and subjects.

The layered structure of experiences emerges in *A Dignified Death*, the story of Eelco, a Dutch man whose mental suffering has led him to choose death assistance and to have it recorded. The film starts by looking back after Eelco's death. The camera records from a distance, on a rainy day, a group of people spreading ashes in the water. Gentle piano music plays in the background as they console each other with hugs. After the opening credits, the viewer hears Eelco's pre-recorded answering machine message stating calmly, 'I'm gone now. I died like you may have read or heard' (translated from Dutch). The short message confirms that death has taken place. The opening suggests that there is nothing left to do to convince Eelco to change his mind, but one can still aim to understand his decision.

However, instead of proceeding to Eelco's explanations, the narration continues from another retrospective angle when the family members – sister, mother and father – talk about their experiences. They share both happy memories and the grief that Eelco's death has brought to them. They also talk about Eelco's mental suffering, his suicide attempt and inability to live without constant support and care. All family members emphasise that despite their

grief they understand Eelco's decision. In this way, the film first builds models of understanding for the viewer.

The need to create models for understanding can also be interpreted as a public recognition that assisted dying, despite its legal status in Netherlands, remains a controversial topic. The narratives of understanding add political consciousness into the film. In the director's statement, Jesse van Venrooij writes that Eelco asked him to record his last stage of dying because Eelco wanted this film to be part of his public project of tackling the stigma on mental suffering. The filmmaker agreed with Eelco's goals:

> I believe that as a society we need to be broad-minded and nuanced on euthanasia. With this work I hope to contribute to that idea. Telling a personal, but also relevant story, without judgement, is my mission. And together with Eelco's request it is my motivation for making this film: to show the other side. (Venrooij n.d.)

Thus, personal becomes political, and understanding is both personal and contextual. In hermeneutic phenomenology, Martin Heidegger's tradition emphasises the interpreting of experiences as a situated act: understanding takes place in historical and sociocultural contexts (Wojnar and Swanson 2007, 174; Laverty 2003, 24). Heidegger (1978) sees that each interpretation is influenced by a person's background and context, which makes pre-understanding and preconceptions part of the meaning-making processes. Hermeneutical phenomenology embraces ideas that the viewers do not perceive the film as an empty canvas, but their preconceptions and thoughts about assisted dying, for example, become integral to the interpretation of the viewing experiences.

A Dignified Death recognises these preconceptions by using media imagery that acknowledges the controversiality of assisted dying. It is precisely this kind of imagery that is applied, when the viewer first hears Eelco explain his experiences. His thinking is introduced through a clip from a newspaper article where Eelco talks about his choice in public, after which the film moves on to a collage of various media interviews. In one of them, Eelco claims that he has nothing to gain from life, that every night he hopes he will not wake up again and how burdensome it is when nothing makes him happy. To media audiences, Eelco talks about his autism-related disorder of PDD-NOS (a pervasive developmental disorder not otherwise specified) and says that while he has tried everything to make things better, his quality of life has not improved. He also talks about his euthanasia process, and at the end of an interview, the journalist does not know what to say, to which Eelco responds that most people wish him a great journey. When Eelco's rationalised explanation is given – again, in retrospect – in media interviews, the film recognises these as public speech acts, as participation in public discussion of what assisted dying

is and in what kind of cases we are willing to accept it. These public speech acts contextualise Eelco's story by giving his background information and situating his story to be a part of public debates, thus adding one (public) part to understanding Eelco's story.

According to Heidegger (1978), the interpretative process works in circular motion: the whole and its parts are constantly compared to each other in a way that increases understanding of the topic. Similarly, supportive family members and the acknowledgement of the public context build Eelco's story by adding layers of understanding. This kind of hermeneutical circle has also been discussed by other hermeneutical phenomenologists, such as Schleiermacher (1998) and Gadamer (1998), who both consider that understanding is enhanced by ongoing movement between the parts and the whole. The hermeneutical circle, in which new material is compared to the conceptual understanding of a topic, has been mostly applied in qualitative research methodology (e.g. Suddick et al. 2020), but a similar process of understanding can also be detected in documentary film viewing.

Mareike Sera (2016, 2–3), for example, discusses the hermeneutical circle of film viewing in relation to Don Ihde's (1986) reading of Paul Ricœur's (1969) hermeneutical phenomenology. Ihde interprets the circle as two-phase transitions. First, understanding seeks to take place through a relationship between expression and experience, in a reflective meeting of prelinguistic experience and (cinematic) expression. The second transition adds an interpretation of expressions through hermeneutics (Ihde 1986, 96–101). Sera argues that in the context of film viewing, the first phase draws from the embodied perceptions of the materiality of the film, which is followed by an induced interpretation that carries cultural and contextual readings. Thus, expressions of the on-screen world are connected to the off-screen experiences and realities (Sera 2016, 3–7). The continuous and circular shifts between these phases explain why the viewer may both understand the filmed subjects' experiences and potentially criticise their decisions.

The latter half of *A Dignified Death* highlights the continuous shifts between witnessing Eelco's experience and contextual interpretation. The film jumps from the retrospective perspective to an observational mode during the last day of Eelco's life. The filmmaker captures Eelco saying his goodbyes, first to his dear friend Nicole. They have a long and intense embrace, which echoes the bittersweetness of the moment. After Nicole leaves, Eelco writes his virtual goodbyes through social media. There are no lengthy explanations in his comments, while the camera witnesses the quiet moments of preparing for the final moment. The farewells of loved ones embody the experience of grief for the viewer.

The following scene, which shows Eelco's death, emphasises haptic witnessing in a situation where desire to understand personal solutions and complex

societal attitudes to assisted dying are mixed. The hand-held camera is constantly moving, as if the filmmaker is not sure where it should be located. It remains out of the way and hovers behind the physicians involved in the situation, showing glimpses of their chins or hands while they explain the process and confirm that Eelco stands behind his decision. The image shifts and moves, constantly returning to Eelco in either mid-shots or close-ups. Eelco's presence, and thus, his experience, is the centre of the camera's navigational pull. Compared to the camera, Eelco remains stoic and becomes the source of composure in the scene. The restlessness of the camera adds contextual debates on whether this kind of death can be embraced, but Eelco's personal experience of calmness invites an interpretation that he is convinced of the acceptability of his decision.

After preparations, Eelco settles in a chair, the cannula is administered, and the valve is opened. Eelco's mother stands by his side, holding his hand. Visually, her presence reassures that the family respects, supports and understands Eelco's choice. While everything else grows quiet and still, the restless camera movements increase. It is the camera that brings rawness and emotional upheaval to the experience, which shows the complexity of witnessing an assisted death, and also, sets it aside from the inanimate death scenes of physical documentaries (Chapter 8). Should one intervene in the name of saving a life or respect the personal plan? Eelco's experience appears to calm the situation; he mutters, 'This is exactly how I wanted it to be,' before dozing off. From here on, the camera slightly calms down, even if its movement continues to remind us of the hand-held filming mode. In his last words, Eelco appreciates all the people who love him. He also starts saying that he has doubts, after which he takes a longer break. The hiatus is almost heartbreaking, letting the mind run wild. The moment is enough to raise every kind of public doubt about assisted dying, adding a further layer to the cinematic expression. However, Eelco reveals that he is not sure whether he wants his last words to be 'Hodor' or 'So long and thanks for all the fish', both being well-known popular culture references. The scene shows that both Eelco and his mother are convinced that this is the best possible solution for him, and this certainness aims to help the viewer to understand why someone might want to die as young as Eelco.

In *A Dignified Death*, access to Eelco's personal experiences increases throughout the film. In the first section, his own voice is almost missing. In its stead, the viewer is offered a model of understanding by other people, as well as contextual struggles related to understanding. Later, when the camera starts to observe Eelco's last day, the viewer is allowed access to his experience, which brings a new layer to the 'circle of understanding', as Heidegger (1978, 32: 153) observes. This hermeneutical circle, indeed, is intended to increase understanding of assisted dying on multiple levels. Susann Laverty (2003, 25)

sees hermeneutical phenomenology as an interaction between the viewer's expectations and the text's meanings. She draws from Gadamer (1998, 295), who finds that interpretation starts when 'a person seeking to understand something has a bond to the subject matter'. Understanding moves beyond re-creating someone else's meaning, Laverty argues. It 'opens up possibilities of meaning', whereby understanding does not force someone's perspective on another, but is about one being transformed through a dialectic relationship (Laverty 2003, 25). Similarly, in Eelco's case, the film seeks to build models of understanding, but it does not demand that the viewers abandon their preconceptions, only that they be open to understanding other people's various realities.

After Eelco's death, the film focuses on how his family and friends move on. The mother takes over the media interviews for Eelco and continues to tell his story. The best friend gets a tattoo that reminds her of Eelco, and the sister tries to manage her emotions of loss by keeping a diary. She writes a letter to Eelco, saying that while she agrees with Eelco's choice, and even feels somewhat relieved, she finds it all to be difficult. Thus, understanding and support remain, yet it does not mean that difficult emotions do not arise nor that there is no grief. Eelco's blog is published posthumously. The family members and friends read these posts aloud for the camera, as a final glimpse into the inner world of Eelco, where he writes about his struggles to engage with other people and the world. In an entry that closes the film, Eelco writes:

> For me, life is an unbearable suffering and hopeless. It's a combination of factors, of course, physically and mentally. But let me be clear. It's mainly the mental aspect that made me come to this difficult decision. I can't and don't want to go on like this. The great paradox of my life is that I'm very scared that I'll impulsively commit suicide in a weak moment. I wouldn't wish that on myself or the people around me. But in all honesty, it's just a matter of time. I want to die, but in a dignified and decent manner. I deserve that. The people around me deserve that. (Venrooij 2018)

During this blog reading, final credits roll, and Eelco's friend Nicole wipes tears from her eyes. It is thus at the very end that the film affords Eelco's own explanation the most time, after providing a model of understanding and acceptance, perhaps in the hope that the viewer is now able to listen and to understand.

Dialogical 'Truth'

Gadamer (1998) gives special importance to dialogue in the processes of understanding. Michael Peters and Tina Besley point out that '[f]or Gadamer,

dialogue is an encounter with the Other in the process of understanding which can be seen as reaching an agreement where reaching an agreement means establishing a common framework or "horizon" and understanding is the "fusion of horizons"' (Peters and Besley 2021, 672). This process compares to Bill Nichols's term 'dialogical truth' in the documentary field. According to Nichols, films that emphasise emotional and personal interaction between the filmmaker and the filmed subjects construct dialogical truth through situated interaction. The dialogical relationship makes the filmmaker a 'collaborator and confidant' and allows the viewer to listen to the filmed subject. The dialogical approach to a social issue, Nichols argues, has a complex relationship with the real. These films do not expect to reveal a certain or generalisable truth, but to enable an open-ended understanding of verifiable experiences (Nichols 2016, 82–4). In other words, dialogical documentary films construct 'truth' in their singular contexts and situations.

The dialogical pattern is visible in Jessica Villerius's documentary *Veda's Choice*, where the filmmaker's presence is a powerful narrative and visual element. Rather than hiding behind the camera, the filmmaker has on-screen dialogues with Veda, a 19-year-old who seeks assisted dying due to mental suffering. The film presents the filmmaker as a confidant seeking to understand why Veda wants to end her life. In a media interview, Villerius says that she was inspired by Veda's letter and request to be filmed:

> This letter, from an 18-year-old on a mission, radiated so much urgency that I had to do something with it. It resulted in a long journey with a lot of sadness and despair but I would do it again tomorrow. The group of young people with a psychiatric background and a death wish deserves a voice. (2Doc.nl 2019, translated from Dutch)

The film starts with Veda crying in a selfie video with a mobile phone camera that she has had enough and wants it to stop. Veda offers no rational explanations why she wants to die. Rather, she provides an embodied sense anguish and suffering. Later, her affective claims are explored through intense conversations between Veda and Villerius. The first time, they sit on a bench while Veda talks about her feelings. The filmmaker nods her head, immersed in Veda's words. Here, the filmmaker stands in for the viewer, who is invited to understand Veda's misery. The camera focuses on Veda's face and her expressions, while the filmmaker is seen in a side profile with her gaze trained on Veda. The attentive arrangement prompts the viewer to prioritise Veda's part of the dialogue.

Similar scenes repeat throughout the film. Veda explains and the filmmaker listens and asks clarifying questions. Veda shares her life with the filmmaker: she was bullied at school, there were troubles at home, she was sexually abused

by a family friend and she was not able to talk to anyone about her experiences. In some discussions, the filmmaker also challenges Veda. For example, after being told by Veda's grandmother that Veda has used a wheelchair since her teens due to a body integrity identity disorder where she feels that her legs do not belong to her, the filmmaker asks Veda if she is physically able to walk. Veda confirms that she can walk, but her inability to move is psychological, which is difficult for some people to understand. The filmmaker again appears in a side profile, and the camera focuses on Veda who sits in a wheelchair by a creek. The filmmaker continues the dialogue by asking what would help her to understand Veda. Gazing slightly downwards, Veda voices her thoughts: she hopes that people would understand that this is not her choice. If she could choose, she would choose to be normal. In this scene, the dialogue form is literally used to increase understanding over Veda's situation.

In addition to the explicit dialogue scenes with the filmmaker, *Veda's Choice* uses other ways to build dialogism. First, the filmmaker interviews people in Veda's life, and the perspectives of her grandmother, a friend and a psychiatrist add various voices that construct a dialogical way of building the circle of understanding. In documentary films, interviews typically add different perspectives and voices into the story (Nichols 2017, 145–6). Mikhail Bakhtin (2011) construes the plurality and polyphony of voices as 'dialogism', where multiplicity enables negotiation of meanings through ideological struggles. In the documentary films, similarly, various voices are brought together to discuss, define, explain and experience end of life. These voices react to events happening to them, to other voices, providing the viewer with various perspectives for meaning-making. For example, Veda's grandmother and friend add supportive voices by arguing that they understand Veda's choice, although they also hope that Veda would still change her mind.

The ideological struggle identified by Bakhtin has a role in Veda's story. Veda's experiences are contrasted with the voice of a psychiatrist working with young people intent on assisted dying. The psychiatrist, who is not against assisted dying, emphasises that young people are obliged to participate in intensive therapy before they can receive a referral for assisted dying. Not only does this interview add contextual information, it is also visually brought into dialogue with Veda's experiences. The psychiatrist says that Veda is not happy about the therapy requirement, which she sees as delaying the inevitable. This is edited together with shots of Veda sitting on her bed, looking sad and inconsolable with the filmmaker by her side. The psychiatrist's professional argumentation for the benefits of therapy as well as the understanding of Veda's frustration and experiences create a narrative dialogue that inserts sociocultural context into Veda's story.

Towards the end of the film, the dialogues between the filmmaker and Veda intensify. The filmmaker increasingly challenges Veda. For example, she

promptly asks 'why don't you just kill yourself', before softening the question by adding 'someone might ask'. Veda argues that suicide would be traumatic for her and for her family and friends, whereas assisted dying would socially acknowledge her emotions. Yet, a few days later, Veda tries to kill herself. The filmmaker picks her up from a psychiatric ward and takes her home, where Veda heads to the bathroom to wash her dirty clothes. The filmmaker sits with her in the bathroom and the intimacy of the space adds intimacy to the dialogue where Veda tells what happened. First, she thought that she could throw herself in front of a car. The filmmaker asks why she stopped. So far, Veda has been facing away from the camera, but now she raises her gaze towards it: 'The way I would die. The driver … And being alone. The fear that it would fail.' In the last sentence, she lowers her gaze again, as if ashamed of considering deviating from her original plan.

The narration jumps to Veda's last therapy meeting, after which she meets the filmmaker on the street. Veda admits that she has learned to manage her emotions better and that her take on life is more positive than it used to be. But she still wants to die. The filmmaker challenges this outcome, which Veda counters by saying that she does not believe anything will help; she fears that her life will derail again. The discussion follows earlier scenes. Veda sits in a wheelchair, facing camera, while the filmmaker is sitting on a nearby bench, gazing up at Veda in a side profile. The filmmaker sits at a lower level and she must look up at Veda, which gives Veda the power position in the scene. The visual composition, again, prioritises Veda's experience as something that others seek to understand.

The film ends with a birthday sequence of Veda turning twenty. At the birthday party, Veda is shown in a lively discussion with her family, and she is more comfortable participating in the conversation as an equal member of the group, both voicing her opinions and listening to those of others. For the filmmaker, Veda admits that she is happy and while she does not know what has changed, she does not want to go through assisted dying right now. From this, the film cuts to an interview with the psychiatrist, who argues that assisted dying wishes are often discussions on suffering. With mental health issues, the patients are commonly urged to do something about this suffering by themselves, whereas their suffering should be better understood and supported. Then, perhaps, there would be less of a need for assisted dying services. This argument frames the visual and narrative choices of the film. Dialogism adds voices, but Veda's voice is prioritised as an attempt to provide understanding and support for Veda. The closing suggests that perhaps suffering, in some cases, can ease if one is heard and understood.

Ethics of Listening

Nichols's article *The Voice of Documentary* (1983, 281) made 'voice' a key concept in understanding how documentary films allow space for various perspectives. Since then, giving voice to people in a marginalised position has been considered filmmakers' key ethical act. Kim Munro (2018), however, maintains that this is not enough. Munro argues that there are so many competing voices in the contemporary media that while there are plenty of opportunities for speaking, the most ethical act would be to listen. This act of listening can provide documentary filmmaking its critical and ethical engagement, because it moves the viewer beyond self-concern towards responsibility over the other (Munro 2018, 279–82). Consequently, while dialogism which allows voices such as Eelco's and Veda's and those of their loved ones to be heard, the ethical act on the viewer's part would be to listen to the multitude of voices. Jennifer Malkowski (2017, 83) argues that the practice where the camera provides a listener to a dying person also highlights the person's individual status. From the viewer's perspective, then, we should talk about the 'ethics of listening', which participates in the understanding process provided by these documentaries.

The ethics of listening unfolds in the documentary *Nathan – Free as a Bird*. Roel Nollet, the director, says on the film's co-fund page that the documentary started from the idea of filming the transgender process of Nathan. When the process failed Nathan's expectations, he became depressed, and the story took another direction. When Nathan asked Nollet to document his process of assisted dying instead, Nollet had to consider whether he was comfortable with the topic. A few days later, Nollet phoned him back, and Nathan reasoned that it was his legal decision and that he wanted the world to know his tale (Nollet 2014b). The filmmaker did not want to tell people what they should think about euthanasia, so he focused on Nathan's, rather than his own, experience:

> When we look through his eyes, we can get a glimpse of his mind too. Away from all the pro and contra lobbies, we can only try to understand what made him decide to do this, and why – for him – this was the only option at that given moment in time. (Nollet 2014b)

In this quote, Nollet uses the word 'understanding' as a key element for the film, where both he and the viewer can search for answers.

In the film, the director places himself in the role of a mediator who listens and asks the viewer to listen with him. Munro (2018, 289–91) argues that a documentary film can engage with active listening by acknowledging, implicating and modelling acts of listening for the viewer. In *Nathan – Free as a Bird*, this happens already during the first shots, where the filmmaker sits by a computer, listens to Nathan's voice recordings and writes his story posthumously. A clip

of Nathan's recordings plays over the image: 'I'm going to talk to you about what is going on in my head.' A close-up of the filmmaker's focused expression, when Nathan's voice declares that he wants to die, emphasises the act of listening, before the filmmaker-narrator declares that this is the story of 44-year-old Nathan who asked for assisted dying because he felt imprisoned inside a female body. This opening confession places the filmmaker (and the viewer) as a listener. It is this person that Nathan talks to and would like to understand him.

The same way as in Eelco's and Veda's stories, the interviews of Nathan's friends and media segments add dialogism to the circles of understanding. The media segments provide background information to Nathan's story and contextual discussion on the ethics of assisted dying. In dialogue with media material, Nathan confesses that his identity traumas go beyond transgender issues. He was a victim of incest as a child; his mother failed to support him and instead humiliated him about his looks. There are newspaper clips where the mother calls Nancy an ugly child and denies that Nathan's death would make her sad. The friends, however, serve as models of understanding. They are sad to lose Nathan, yet they have listened to Nathan's requests and support him. One of them even speculates that Nathan may have wanted to become a man because he was rejected as a daughter; maybe he thought he could become lovable as a man. These dialogical scenes enhance the viewer's understanding of the traumas behind Nathan's mental suffering.

The plurality of dialogism provides the viewer with different perspectives that can make the whole of Nathan's experience understandable, but it is the private moments of the film that emphasise the viewer's responsibility of listening. Munro (2018, 285–6) adds that listening builds on affective responses to the other, because the listener is willing to give up a power position in favour of reaching beyond oneself and engaging with the other. Listening, as Jan Grue (2022, 11) argues, adds truth value to experiences and makes it difficult to question these arguments. In *Nathan – Free as a Bird*, the affective relationship with the viewer is emphasised in the private moments at his home, where the filmmaker and the viewer become his trusted listeners.

The first intimate section takes place quite early on the film. The sequence starts with Nathan organising his home and belongings to be donated after his death. At the same time, he explains to the filmmaker why he seeks assisted dying to escape his suffering. He tells about his failed penis operation. The film includes a few pictures of his deformed penis, to confirm the claim, not to linger. Nathan argues that every time he goes to the bathroom, he needs to encounter this failure: 'You don't feel like a human. You feel like a freak.' The sequence continues in the bathroom, where Nathan stands in front of a mirror, removes his shirt and looks at himself in the mirror. After some dialogical jumps, where a friend, for example, says that suffering cannot be seen on the outside, the narration returns to the bathroom, where Nathan confesses being

disappointed by his looks. An extreme close-up of his eyes returns his gaze before the framing readjusts, showing Nathan talking to his mirror reflection and pointing out his flaws, such as the deformed result of breast removal.

Glen Donnar argues that mirrors are important for constructing, strengthening and performing an identity, because they function in-between public and private. While the bathroom refers to privacy, the mirror opens up to other spaces, how others see you. Mirrors connect private performances of self to public constructions of self. In (fiction) films, Donnar continues, mirrors tend to mark male inadequacy and self-doubt related to the performed self (Donnar 2015, 181, 188–9). This argument resonates with Nathan's experience as he appears to feel imprisoned by his body. The bathroom scene also reveals the discontinuity of Nathan's public and private self. Out in public, among his friends, Nathan appears functional and well spoken, but when the layers of clothes and public masks are removed, he finds no peace with himself. When the viewer is allowed to access this private space, the viewer is also given responsibility to listen to these personal confessions.

Further along the film, the affective and private relationship between Nathan and the viewer deepens. Nollet says that Nathan sank into a deep depression after his failed gender construction operations:

> There were times when I called him he said he was so depressed he had locked himself up and didn't want to talk to anyone. I suggested to give him a small camera, so Nathan could record himself on the moments he needed to talk to someone the most, and no one was there. He agreed. (Nollet 2014b)

Figure 9.1 Nathan in his bathroom, looking at himself in the mirror, tears in his eyes (Nollet 2014a).

Some of these privately filmed scenes are part of the documentary. For Munro (2018, 283), such self-recorded testimonials serve as evidence that there is someone one can talk to and that someone is listening. Thus, without even the filmmaker's presence in the scenes, the viewer becomes the most trusted confidant and listener, which highlights the ethical requirements over these encounters.

One night, when Nathan has trouble sleeping, he films himself in a walk-in closet. The dark and shaking image of a close-up of his face emphasises the emotional tension of the moment. Nathan says that he cannot find peace, nor does he feel joy. In another self-filmed scene, Nathan declares that he prefers keeping his suffering to himself, because he does not force others to share his sadness, anguish and suffering. A tear runs down his face, when he says people cannot know how he experiences things, how broken he is. These self-confessionals, filmed in privacy and revealed for the viewer give the viewer the privilege and the burden of being the one who Nathan trusts to share his suffering with.

The last sequences of the film focus on Nathan leaving his goodbyes and preparing for death. Here, the dialogism between Nathan and his friends intensifies when some of his friends ask Nathan to change his mind, but Nathan sticks with his decision. In the parking lot of the hospital where Nathan goes to die, the filmmaker captures Nathan in a close-up, with tears in his eyes, when he says that he is looking forward to being free. This comment appears to be directed towards the viewer who has seen and heard his private confessions, and thus, might be able to understand why Nathan does not want to back down. The viewer is placed into a position where the circle of understanding is well-constructed, perhaps even better than with the people in his life.

Around Nathan's deathbed, however, any doubts are set aside. A friend reads a poem that speaks to the friends' desire to understand Nathan's feelings and decision: 'You felt lonely, and that's why we let you leave.' When a cannula is inserted into Nathan's hand, the viewer hears his voiceover giving life instruction. He instructs people to enjoy small things about life, to make room for affection and to respect others. These are the last messages Nathan wants everyone, including the viewer, to listen to. A close-up of dripping medicine indicates that the moment of death is close. Nathan bids farewell. His death follows in seconds, leaving the friends standing solemnly by his bed before the image fades to black.

After Nathan's death, the film repeats the opening scene. The filmmaker sits in his study, writing a book and listening to Nathan's recordings. One last time, the scene draws attention to the act and the ethics of listening. The filmmaker's words on the film's co-fund page emphasise the importance of listening: 'I felt like his [Nathan's] voice was being heard for the first time. On the day he died, I found a short note in my camera bag. He thanked me

for listening to him' (Nollet 2014b). This anecdote reveals the ethical power of listening – while many of us can talk, perhaps more of us should be able to experience being listened to. Perhaps it is the act of listening that has the power to transform us and our preconceptions.

Refusing to Listen

In *The Good Death*, the ethics of listening takes another turn. Whereas Eelco's, Veda's and Nathan's stories take place in contexts where assisted dying is legalised, Janette lives in England, where assisted dying remains illegal. This contextual information adds a twist to her story. To be able to die assisted, she says, she has told so many lies to so many people. She has had to strategise how to make people see that there is really no alternative. The film, indeed, includes plenty of scenes where others refuse to listen to and understand Janette's choice. For example, her physicians have refused to help her and have instead threatened to admit her to hospital for her psychological issues, and Janette had to lie that she had changed her mind about assisted dying. She also lies to some friends that she will go and live with her son, whereas in reality, she is packing up her things to die in Switzerland. Janette's biggest struggle for understanding is with her daughter, who asks her mother to change her mind until the very end. The daughter claims to understand but keeps offering alternatives. Janette confesses to the camera that 'all they [her son and daughter] are now doing is they are making me angry and upset'.

The desire to change Janette's mind continues in Switzerland, where both of her children accompany her. When she meets with the physician from the clinic that offers assisted suicide, Janette clings to her. She cries and repeats the words 'thank you', not only thanking for the assistance, but for understanding. The physician even explains to Janette's children that their mother is prepared to die and is in her right mind. The doctor defends Janette's decision for her, while the children sit quietly and listen. They also promise that they will not stop Janette. However, the daughter, who promises to support her decision, asks her mother to consider postponing the death. Janette remains calm and once again explains her decision to her children, who keep interrupting. Here, Janette takes a position of active listening. She supports her children by saying that she knows her decision is difficult to accept and that she is sad to cause misery to others.

Janette becomes the one who listens to others and tries to adjust her explanations so that the others could accept them. This context emphasises the viewer's role. For Janette, the viewer becomes a confidant, a listener who might be able to understand her. At the level of narration, the desire to win the viewer over is evident in the constant use of Janette's voice. While the filmmaker films Janette in everyday activities, such as gardening or getting the mail, Janette's voiceover keeps asking for a listener. In a calm and carefully pronounced

manner Janette talks about her daily difficulties and her wish to avoid further suffering. As a solution, she wants to have control over her own death. The explanations are probably similar to those that she has offered to people in her life, but this time, she asks if the viewer could understand her experiences and reasoning.

The visuals of the film support Janette's experiences of being left alone with what she wants. The narration repeats shots of waking up. This is an overhead image, shot from the ceiling above the bed. The first time, it shows Janette waking up alone in her bed. She breathes heavily and stares at the ceiling before slowly and carefully placing her feet on the floor. She needs support from a cane and the wall to move towards the bathroom. Her voiceover says that life is not fair, but she has learned to accept her disability. The intimate space, the bed and the bedroom, reveal her physical fragility, but also her resilience and determination. Soon, there is another bed scene, of Janette's son waking up. The camera, once again, takes an overhead shot. The image shifts to an eye-level shot when the son places his feet on the floor, more agile than his mother, and easily slips his feet in a pair of jeans. The son is physically more able, yet the comparison of the images reveals his potential future of a fragile physical condition. Bed scenes feature again in the latter half of the film when Janette and her children travel to Switzerland for Janette's death. On her last night at home, after packing her bags, Janette goes to sleep. In the dark bedroom, the camera again gazes from overhead, offering a last moment of considering of staying at home, in your own bed.

The overhead shots add dramatic visualisation to the film, but also guide the viewer's attention to the privacy of experience and the role that the viewer has in witnessing these intimate moments of waking up, the moments between being vulnerable while sleeping and moving towards the public parts of day. The scenes also prepare the viewer for Janette's deathbed scene. During the assisted death, the camera stays on eye-level, which highlights the role of the observer rather than that of an intimate listener. After Janette opens the valve to receive medication, she lies on a bed, quietly smiling, while her daughter caresses her hand and her son sits on a sofa. When she starts breathing heavily and closes her eyes, the image fades to black and quiet music starts.

The bed theme returns once more. After Janette's death, an overhead image of the son sleeping on a bed is repeated. This returns the viewer's mind to the increasing fragility of Janette, which might be the son's fate as well. After waking up, the son admits that he is sad to see his mother gone. He hopes that the choice for assisted dying will be understood and acknowledged when his own condition has reached that stage. He does not know what his choice will be, but he hopes there is a choice. The film ends here, with images of the sea and sky juxtaposed to being confined in one's own body and bed. 'Euthanasia', Greek for good death, is written over the scenery as closure.

Conclusion

The dialogical documentaries discussed in this chapter provide personal justifications for choosing assisted dying. Through stories of a person's journey, these films serve as models of understanding. The narrative approach highlights these end-of-life decisions as individual and singular choices. The viewer is not expected to make a similar choice, or even accept legalisation of assisted dying at a general level. Instead, the viewer is presented with models of understanding to see why this particular person ended up in this situation and this particular choice. From the perspective of the filmed subject, the desire of being understood also relates to alleviating anxiety. The protagonists do not fear death, but see it as a relief. What they fear is not being understood. In comparison, understanding adds value to their life and death.

In order to emphasise the polyphony and to acknowledge the mixed attitudes towards assisted dying, these documentaries utilise a dialogical format. The viewer has access to the voices of those who wish to die, but also to voices of their families and friends, and occasionally of authorities, such as physicians. These voices add contextual understanding of the situation, but also provide personal models for listening. In total, the dialogues contribute parts to the whole, and increase the potential for the viewer to understand the complexity of the situation. While the focus is on the personal experience of the filmed subject who seeks to die, none of the films denies that death and loss give rise to difficult emotions. Instead, they openly address that it can be hard to let go, even when you want to understand and support the person you care about.

Thus, the argumentation in dialogical documentaries about assisted dying draws from affective and emotional processes of understanding, instead of focusing on rational reasoning for or against assisted dying. The personal becomes political through emotions and experiences. As such, the ethical connection to assisted dying builds through the ethics of listening instead of debating normative ethical guidelines. In dialogical documentaries, listening takes place on various levels. First, the person wanting to die talks, and their friends and families listen, try to understand and bring their perspective to the dialogue. Their reactions can model listening and understanding for the viewer, or in some cases, challenge this process, which allows the viewer to see how the refusal to listen can be difficult for the person seeking understanding. Second, the filmmaker provides the position of a listener, either explicitly in the images or as a narrative position to whom the main subject talks. The filmmaker also represents the viewer, who is invited to listen and to understand. In some cases, where the filmed subjects have self-recorded their experiences, the viewer's role as an ethical listener is enhanced. The viewer is asked to prioritise the dying person's experience before making any moral judgements.

While there is no obligation to transform one's values related to assisted dying, these films ask the viewer to understand singular contexts where a desire for assisted dying can emerge. The 'ethics of listening' becomes an affective and emotional process, with a potential for transformed thinking and feeling. Instead of demanding, these dialogical documentaries gently ask the viewer to understand, and then perhaps (re)consider how they feel about assisted dying.

References

2Doc.nl. 2019. 'Veda beslist zélf'. 2Doc.nl. 24 April 2019. https://www.2doc.nl/documentaires/2019/04/veda-beslist-zelf.html. Last accessed 25 January 2023.

Abulad, Romualdo E. 2007. 'What Is Hermeneutics?' *Kritike* 1 (2): 11–23.

Bakhtin, Mikhail. 2011. *The Dialogic Imagination: Four Essays*, edited by Michael Holquist. Translated by Caryl Emerson and Michael Holquist. First published 1981. Austin: University of Texas Press.

Cineuropa. 2020. 'Tomáš Krupa, Producer, Hailstone: "Emotions Are the Only Thing We Have"'. *Cineuropa – the Best of European Cinema*. 20 February 2020. https://cineuropa.org/en/interview/385611/. Last accessed 25 January 2023.

Donnar, Glen. 2015. 'Monstrous Men and Bathroom Mirrors: The Bathroom as Revelatory Space in American Cinema'. In *Spaces of the Cinematic Home: Behind the Screen Door*, edited by Eleanor Andrews, Stella Hockenhull, and Fran Pheasant-Kelly, 180–93. London; New York: Routledge.

Eliot, T. S. 1928. 'A Song for Simeon'. In *Ariel Poems*. London: Faber and Gwyer.

Fariña, Juan Jorge Michel, Irene Cambra Badii, and Ailen Provenza. 2016. 'Euthanasia and Assisted Suicide: A Cinematographic Approach to the Death That Hurts the Most'. *Jahr: Europski Časopis Za Bioetiku* 7 (2): 293–305.

Gadamer, Hans-Georg. 1998. *Truth and Method. Second, Revised Edition*. First published 1960. New York: Continuum.

Grue, Jan. 2022. 'The Death of Others. On the Narrative Rhetoric of Neoliberal Thanatopolitics'. *Disability Studies Quarterly* 42 (1). https://doi.org/10.18061/dsq.v42i1.7799.

Heidegger, Martin. 1978. 'Being and Time'. Oxford: Blackwell.

Ihde, Don. 1986. *Hermeneutic Phenomenology: The Philosophy of Paul Ricoeur*. First published 1971. Evanston, IL: Northwestern University Press.

Kennedy Schmidt, Lawrence. 2016. *Understanding Hermeneutics*. London; New York: Routledge. https://doi.org/10.4324/9781315539331.

Krupa, Tomáš. 2018a. *The Good Death*. Documentary. ARTE; Czech Television; Golden Girls Filmproduktion.

———. 2018b 'Director's statement'. The Good Death by Tomáš Krupa. 2018. https://gooddeath.net/. Last accessed 25 January 2023.

Laverty, Susann M. 2003. 'Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations'. *International Journal of Qualitative Methods* 2 (3): 21–35. https://doi.org/10.1177/160940690300200303.

McAdams, Dan P. 2011. 'Narrative Identity'. In *Handbook of Identity Theory and Research*, edited by Seth J. Schwartz, Koen Luyckx, and Vivian L. Vignoles, 99–115. New York: Springer. https://doi.org/10.1007/978-1-4419-7988-9_5.

Malkowski, Jennifer. 2017. *Dying in Full Detail: Mortality and Digital Documentary*. Durham, NC; London: Duke University Press. https://doi.org/10.1215/9780822373414.

Munro, Kim. 2018. 'From Voice to Listening: Becoming Implicated Through Multi-Linear Documentary'. In *Critical Distance in Documentary Media*, edited by Gerda Cammaer, Blake Fitzpatrick, and Bruno Lessard. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-96767-7.
Nichols, Bill. 1983. 'The Voice of Documentary'. *Film Quarterly* 36 (3): 17–30. https://doi.org/10.2307/3697347.
———. 2016. *Speaking Truths with Film: Evidence, Ethics, Politics in Documentary*. Oakland: University of California Press.
———. 2017. *Introduction to Documentary, Third Edition*. Bloomington: Indiana University Press.
Nollet, Roel. 2014a. *Nathan – Free as a Bird*. Documentary. Coccinelle Film Placement.
———. 2014b. 'Nathan Free as a Bird'. Indiegogo. 2014. http://www.indiegogo.com/projects/975773/fblk.
Peters, Michael A., and Tina Besley. 2021. 'Models of Dialogue'. *Educational Philosophy and Theory* 53 (7): 669–76. https://doi.org/10.1080/00131857.2019.1684801.
Ricœur, Paul. 1969. *The Symbolism of Evil*. Translated by Emerson Buchanan. Boston, MA: Beacon Press.
Schleiermacher, Friedrich. 1998. *Hermeneutics and Criticism and Other Writings*, edited by Andrew Bowie. Cambridge: Cambridge University Press.
Sera, Mareike. 2016. 'The Value of Hermeneutics to Film Phenomenology: Michelangelo Antonioni's L'eclisse'. Unpublished paper. https://www.academia.edu/17522351/The_value_of_hermeneutics_to_film_phenomenology_Michelangelo_Antonioni_s_L_eclisse. Last accessed 27 January 2023.
Suddick, Kitty Maria, Vinette Cross, Pirjo Vuoskoski, Kathleen T. Galvin, and Graham Stew. 2020. 'The Work of Hermeneutic Phenomenology'. *International Journal of Qualitative Methods* 19 (January): 1609406920947600. https://doi.org/10.1177/1609406920947600.
Venrooij, Jesse van. 2018. *A Dignified Death*. Documentary. Film Moment.
———. n.d. 'A Dignified Death'. FilmFreeway. https://filmfreeway.com/adignifieddeath. Accessed 25 January 2023.
Villerius, Jessica. 2019. *Veda's Choice*. Documentary. BNNVARA & Posh Productions.
Wojnar, Danuta M., and Kristen M. Swanson. 2007. 'Phenomenology: An Exploration'. *Journal of Holistic Nursing* 25 (3): 172–80. https://doi.org/10.1177/0898010106295172.