

Hearing Loss: Listening to End-of-Life Transitions, an Arts-Based Approach to Midlife Mourning

Jill Halstead and Wolfgang Schmid

In this article we share our personal stories of the loss of a parent during the COVID-19-pandemic. The crisis demonstrated how the medical-scientific apparatus effectively responded to a global health emergency, but also revealed how end of life processes are professionalized in neoliberal societies, where dying and death are outsourced and sanitized, and grieving is increasingly pathologized. Drawing on our backgrounds in music and music therapy, we trace our own experiences of loss to illustrate aspects of our individual and shared bereavement process as it emerged over a 24-month period. We take an intuitive, arts-based, feminist-philosophical approach, where dying and mourning are understood as personal, social, and political events. The article is structured around the presentation of eight poetic fragments from *Hearing Loss* (Schmid and Halstead, 2023) a co-created digital exhibition on the theme of mourning which includes soundworks, images, narratives, short films, and poems. Through these intimate multi-modal pieces, we reflect how we *do loss*, and how we might speak about, and listen to, the existential, relational, and transitional experience of losing a loved one in midlife. Our work argues that practices of grieving should be encouraged, shared, and valued to ensure the *mournability* of every life.

Mourning is a way of attending to the world, a way of acknowledging that we are vulnerable to loss and to the suffering of others, a way of acknowledging that we are bound to each other by bonds of commonality.

Judith Butler, *Precarious Life*, 22.

Loss in the time of COVID-19

Lockdown and social distancing. Border closures, travel restrictions, and quarantine. Closed schools, restaurants, and public places. Severe visitor restrictions and disinfection measurements at hospitals and homes for the elderly. The global spread of COVID-19 led the World Health Organization (WHO) to declare the outbreak a public health emergency of international concern and as a pandemic on the 11th of March 2020 leading to some form of lockdown across almost all countries of the world (Onyeaka). These measures confronted people around the globe with profound changes in their everyday life. A new sense of our human vulnerability invaded people's consciousness as talk about death, dying, and grieving became unavoidable.

As of December 2022, WHO reported 651,918,402 confirmed cases of COVID-19, including 6,656,601 deaths. People died on locked hospital wards, often isolated and alone, with masked hospital and intensive care staff present, unable to communicate with family, except electronically. Families and friends were forced to witness death and dying from a distance, not allowed to care for their loved ones in their last days, say goodbye, or even perform traditional rituals of grief and mourning. In their 2022 report *The Value of Death* (Sallnow et al.), *The Lancet* Commission brought together a diverse international group including health and social care professionals, social and health scientists, philosophers, artists, community workers, activists, patients, and religious leaders. Their report points to how the pandemic revealed that death and dying are predominantly professionalized, medicalized, and institutionalized in high-income countries in Western societies. This professionalization has displaced death from everyday life, which in turn has resulted in a weakening of the folk, community, and familial knowledge of death. Medical historian Brandy Schillace sums up the situation when she states that Western societies have lost loss, "during a century and a half of sanitisation and silence" (Schillace, 2).

While we might quite rightly respond that the crises caused by COVID-19 could not have been met so effectively without the present health care system and its advanced knowledge and technology, the report reminds us how a highly professional apparatus has pushed the roles of families and communities to the margins in caring for the dying. Relationships and social networks have been replaced by end-of life care specialists and protocols. Referring to the extreme conditions during the COVID-19 pandemic, *The Lancet* report finds, like Schillace, that many cultures have *lost loss*, identifying an alarming lack of contemporary loss practices, with a shortage of familiarity, of skills, and knowledge around death, dying, and grieving. As death and dying challenge modern societal narratives of faith in growth, technological innovation, and progress, there is increased pressure to avoid or repress loss. Ideals about how we should cope with death are evidenced particularly in the many ways grief has become pathologized. For example in 2018, Prolonged Grief Disorder (PGD) was formally included in the 11th version of the International Classification of Diseases (ICD-11) (Eisma et al.). To meet criteria of PGD one needs to experience abnormally persistent and pervasive longing for the deceased and/or persistent cognitive preoccupation with the deceased, in combination with intense emotional pain (like, for example, sadness, guilt, anger, denial, blame), that exceeds six months and/or the period sanctioned within the context of specific social, cultural, or religious norms (Eisma et al.).

Such examples clearly describe the societal expectations around grieving and the ways that coping with loss can easily become a matter of individual fragility and failure, that can result in bereaved persons becoming marginalized. It is against this background that *The Lancet* commission reminds us of the need to retrieve death and integrate it back into everyday life. Public conversations about bereavement need to become more commonplace, discussed through the media, in film and television, in schools and communities, to facilitate open

dialogues that build understanding and initiate change.

Yet, in practice how do we begin to change attitudes to something as profound as death, dying, and grief—of people close to us or ourselves? How do we create safe spaces for sharing the personal, familial, or social transitions

That moment is so personal, so intimate, so crushing, full of mixed hope and despair, it is little wonder most people want to avoid thinking or talking about it. But (...) dying is a process carried out by the living. It is, in fact the most challenging and daunting experience of life. (Schillace, 27)

that occur when we experience dying and loss? Through our own research work and practice in music and music therapy in

end-of-life and loss, we have engaged with these questions professionally, focusing specifically on understanding how dying people and their families *do loss*. Given our backgrounds it was natural to approach how we *bear loss* through engaging with what music and other forms of aesthetic expression offer to such processes. Our aim with this article is to take an arts-based, experimental approach to these questions by exploring the phenomena of mourning through sharing our own experiences.

Our shift in focus from documenting other people's stories to documenting our own was totally unforeseen. In the middle of our research work into loss, we were suddenly faced with these experiences ourselves when in the same week in February 2021 Wolfgang's father and Jill's mother died. In experiencing the event of death at the same time we entered a period of mourning together. At this point the boundaries between professional knowledge and private emotions, family life and work life, and our long-standing relationship as colleagues unravelled, as we shared the strange coincidence of this happening to both of us, at the same time, whilst we were working on the very topic of loss.

The dialogue that emerged between us in the immediate aftermath of bereavement began with a series of SMS messages, emails, and brief telephone

conversations offering words of support. Over weeks and months, the dialogue continued and deepened as we shared more personal thoughts in conversations, most often happening online due to the lockdown. We developed a new companionship through the comparing and sharing of our experiences. Like many others, we often found it difficult to articulate the affective and emotional qualities coherently, as at times such experiences defied words and the usual patterns of verbal expression. Instinctively we began to draw from the expressive bodily practices we know well from our work in music and music therapy, and we moved to arts-based modalities as a way of making sense of our situation. As verbal dialogue transitioned into a form of *aesthetic answering*, a source of self and mutual care that strengthens an embodied intersubjectivity through self-disclosure and reciprocal understanding¹, our creative process began to include musical improvisation (alone and jointly), musical composition, and poetic and visual storytelling.

Around eight months after our bereavements we made the decision to formalize and share these materials with others. This was an important step in relation to our professional practice, which had been committed to encouraging other people to share their stories of loss. The result was a work titled *Anatomy of Loss* (Halstead and Schmid) a multi modal arts-based exposition published in The Research Catalogue—an international database for artistic research. The work is comprised of a series of co-created materials including sound works,

I did not plan to write this book. The book came to me. It started with passionate poetic laments of my beloved's passing. I needed to cry my devastation out loud – very loud. (Lykke, 199)

images, narratives, short films, and poems that illustrate aspects of our individual and shared mourning as it emerged over

¹ Aesthetic answering is a technique used in art therapy that involves using artistic expression as a way to explore complex emotions and experiences. It is based on the idea that artistic expression, whether through visual art, music, dance, or other mediums, can provide a powerful and meaningful way to communicate and make sense of our inner experiences (Knill et al.).

a 24-month period. The exposition is made up of a series of artistic exhibits, with each representing a moment of mourning, a fragment that represents one small part broken off the stream of our individual and joint experiences. Curating these materials into an arts-based exposition has allowed us to explore and balance a range of complex and contradictory polymorphic experiences of sadness and hope, vulnerability, distress, resilience, and denial. In this way we want to carry on the practice and tradition of the arts being helpful in processing loss and supporting mourning (Davidson and Garrido). In particular, we focus on everyday aesthetic practices such as taking photographs, drawing, engaging with music, and writing poems or short stories.

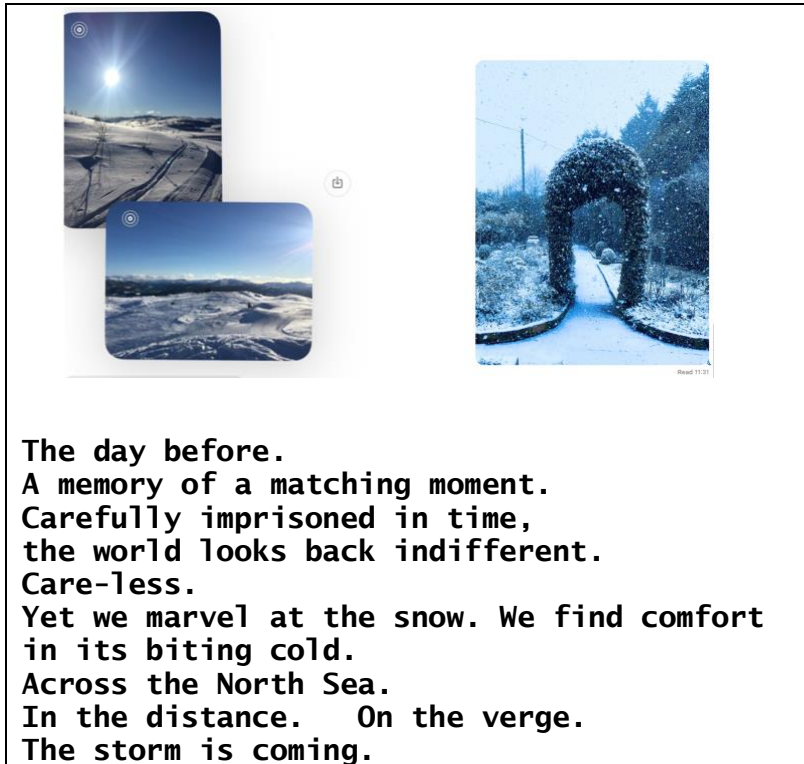
Overall, in this article, we intend to create and hold a space for each individual reader, so that they can approach the text, the quotes, and exhibits in it, almost like visiting an exhibition. We as authors suggest *one* possible way of doing this by providing a certain order of exhibits, text, and quotes. However, the reader should be free to find their own way through the article, maneuver through the piece, turning to the exhibits in the article and the exposition on Research Catalogue, and thus find their own, personal mode and pace of involvement and sense making. To us, this is an embodiment of our methodology and an argument for the individuality and situatedness of mourning processes, that cannot be standardized.

It should be noted that *Anatomy of Loss*, and the processes through which it was created, were not planned but instead emerged intuitively and coincidentally over time, only beginning to gain shape and form over many months. As the work shifted from personal dialogue to public sharing we have engaged in a constant dialogue about how much we would or could share our stories. Sharing a personal story on a difficult subject can be empowering and restorative, but it also can be exposing in a way that risks increased vulnerability, and we are mindful of the potential consequences of taking such a step. The open-ended

nature of the work published in the Research Catalogue means that we keep *Anatomy of Loss* as an unfinished work-in-progress that we continue to add and remove materials from as feels appropriate. Like the exposition, our dialogue also remains ongoing.

For the purposes of this paper, we have chosen eight fragments from the published exhibits in the *Anatomy of Loss* exposition. In the following, we do not list these fragments in a chronological order or present them in a linear way. Rather, each piece comes with its own phenomenological idiosyncrasy, as it occurred and took shape in our collaborative dialogue. The fragments are examples of our responses to loss and how relationships to ourselves and others were challenged in manifold ways. They form a repertoire of mourning that gives insight into the transitional and relational aspects of mourning, highlighting the potential of the arts to express and share grief and allow reflection on how bereaved identities are entwined through collective body memories and relational rituals.

***Crossing a threshold* (Image/text, February 7-12th 2021)**



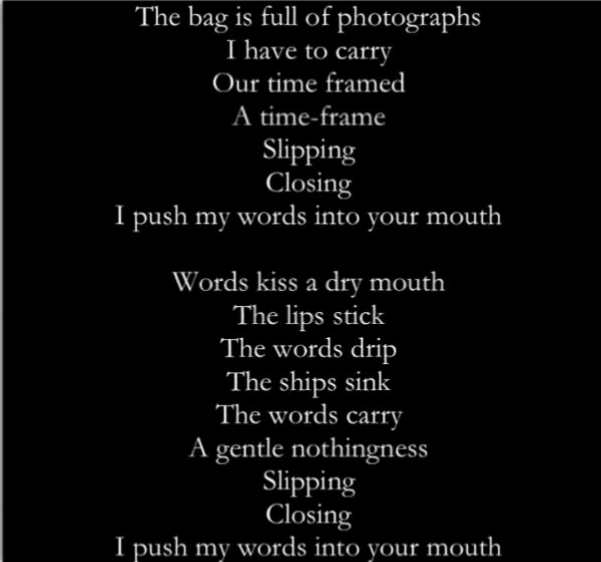
The death of a parent is a significant mid-life transition faced by many people. Such loss is understood to be part of the natural progression of the aging cycle and therefore something that receives relatively little attention. Yet, the two phased life transitions of losing

one and then both parents, is a wholly transformational event in middle age, as adult child becomes adult orphan. Although the circumstances around the death of our parents were quite different, many other aspects of the experience were similar and shared, not least coping emotionally and practically with the death of a loved one when separated by national borders during the extraordinary period of the pandemic lockdowns.

Loss is a threshold. Death is both an individual and shared event, a relational rupture that forces reorganization of the relationship with the lost person but also a reconfiguration of the self and its place in the surrounding world. Receiving the news that someone has died, or being with someone as they die, is a transitional moment when all is changed. The everyday familiar is disrupted and for a time the world shifts, everything looks and feels different. Yet at the

same time the world looks back on us unchanged and unmoved—a disturbing comfort.

Words I put in your mouth (Poem, September 2021)



The bag is full of photographs
I have to carry
Our time framed
A time-frame
Slipping
Closing
I push my words into your mouth

Words kiss a dry mouth
The lips stick
The words drip
The ships sink
The words carry
A gentle nothingness
Slipping
Closing
I push my words into your mouth

Mourning describes a personal or collective response to the death of a person. It encompasses a wide range of complex socio-cultural practices and rituals that individuals or groups go through following the death of a significant person. Forms of mourning differ considerably across cultures and time-periods but traditionally, in the period following death, a range of private and public behaviors are initiated that may continue over days, months, or even years. These practices are often both idiosyncratic and socially determined, and can involve wearing particular clothes, withdrawing from public life, and attending to a range of rituals where grief is displayed publically as a family grouping and/or community. As society has looked towards more medicalized support for how to cope with dying, traditional public forms of mourning are often seen as archaic, or at worst disturbing.

Science might try to explain why we grieve but no one can tell us how to grieve in today's world. Just 'knowing' that conflict causes the body to release an inflammation-causing protein... or that a loving and familiar touch eases sadness because the brain releases neurotransmitters like oxytocin during 'moments of tenderness', does nothing to support one's actual emotional state during such times. In the midst of deepest sorrow, the brain isn't much help. It's the doing that matters... (Schillace, 1995).

It is notable that the word mourning is rarely found in the modern medical or health orientated literature, where discussions often use the terms *grief*, *bereavement*, *loss* and, more recently, *doing loss* (Reckwitz). It is noteworthy that all these terms focus on describing an emotional

state (*grief*) or denoting the status of someone who has experienced the death of a loved one (someone who has been bereaved). The often-used term *loss* is a much broader term, not only used in connection with death, but to describe the more general disappearance of something from the temporality and materiality of our social world (Reckwitz). We would argue that a step towards changing attitudes to death is to focus more on mourning as phenomenon. The concept, in this context, implies a greater focus on expressing experiences around the event of death, and the ways social and cultural norms channel and shape such expressions.

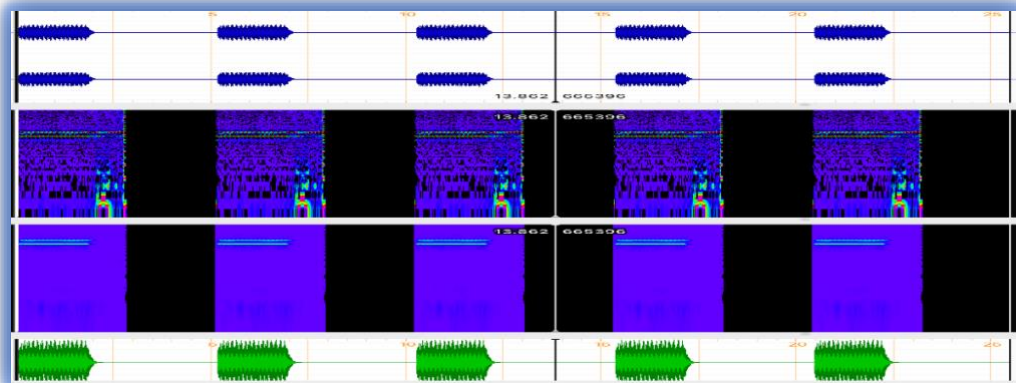
It is in the work of feminist philosophers such as Judith Butler and Nina Lykke that we have found a focus on mourning that challenges common narratives surrounding loss in neoliberal societies in ways which understand mourning as a personal, social, and political event. In their book *Precarious Life* (2004), Butler explores the relationship between mourning, violence, and precarity, the condition of being vulnerable or at risk, arguing that violence and precarity shape our lives in interconnected ways and that the processes of mourning can be a powerful means of resistance against violence and injustice. She examines the ways in which social and political structures

morbid | 'mɔːbrɪd | adjective **1** characterized by an unusual interest in disturbing and unpleasant subjects, especially death and disease: **2** *Medicine* of the nature of or indicative of disease:

DERIVATIVES **morbidness** noun
 ORIGIN mid 17th century (in the medical sense): from Latin *morbidus*, from *morbus* 'disease'.

contribute to the precariousness of certain groups, and the ways individuals and communities can resist and challenge such forces. In her most recent work *Vibrant Death*, Lykke takes an autophenomenological approach to explore the taboos around her excessive mourning of her beloved. She argues that neither Christian nor secular scientific materialist discourses were able to provide satisfactory answers to the existential questions prompted by the death of her life partner. Instead Lykke turned to poetry and other expressive forms, such as opera, art, and literature as a way of philosophizing these questions. According to Lykke, individual experiences of grief, or what she terms the *mourning I* have often been present in the arts, where the focus has been on poetic expression, embodiment, and affect, rather than on the philosophical or rational contemplation of death. In documenting and analyzing her own grief using artistic methods, Lykke developed profound insights into how mourning permanently changed her relationship with her life partner, her sense of self, and her relationship with her material surroundings.

Lykke's approach to understanding death through her mourning is an excellent example of the ways poetic and affective modes can be a means of “knowing and showing” (Kemp, 116) the *mourning I*. In our collaboration we know and show grief through co-creating multi-modal poetic materials. This shared process reveals important aspects of the relational and communal aspects of mourning, what we call the *mourning we*, and explores the ways this *we* emerges and finds meaning in experiencing grief.

A Song Without Words (Audio Piece, 13 minutes, November 2022)

Sonic profile of a ringing phone.

Jill: She was hospitalized at the height of the pandemic. The week in January 2021 when the National Health Service in the UK experienced the highest numbers of patients ever recorded. The system was completely overwhelmed. When she entered the hospital, all contact was lost; we were not allowed visits or phone calls either with her or the staff caring for her. During the lockdown the news was filled with stories of how telephone and video calls were a lifeline for those isolated, but our reality was quite different. When we found ourselves in a system at breaking point, there was no one available to help her use the technologies, no one had time to even answer the phone, so there was no such relational lifeline in those dark days. The loss of contact felt like an abandonment of her. A brutal severing of the lifelong intimacy in her moment of greatest need.

For seven days all we could do was call the hospital and wait for news. We called from a mobile phone—listening together on the loudspeaker. Each day we spent hours just trying to get through to someone—anyone. It was a desperate and comforting ritual primarily because it was something we could do.

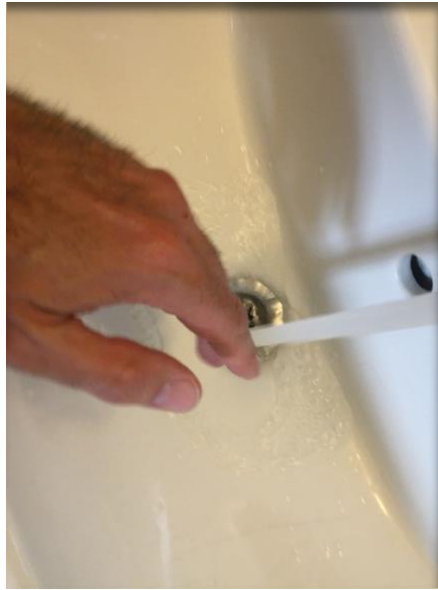
Through this time the ringing phone became a soundtrack for our separation, a sonification of

the isolation and the distance between us all. Its hypnotic chain of sounds were repeated over many minutes, which turned into hours, which turned into days; over this unfolding time the sound became twisted, distorting into new patterns and rhythms as my ears played a strange game with the incessant sound. As the phone rang and rang, I heard changes to the pace of the ringing, occasional skips and pauses in its rhythm, in my imagination I heard it speed up and slow down. I could even transform it into the rhythm section of my favourite songs, yet I knew that the ringing remained utterly unchanged. The situation remained utterly unchanged. Repeated sounds, like grief itself, is well known for its ability to bring about altered mental states. I lived these days in a daze riding this temporal phone-train to nowhere, unable to escape it, or myself. Calling the hospital was both a way of killing time, marking out time and keeping hope alive, the ringing phone our sonic question to which there was no answer. When on day seven the phone stopped ringing, the voice informed us that everything had been tried but nothing could be done. "So sorry. Goodbye."

Criteria for prolonged grief disorder (PGD) according to the International Classification of Diseases-11 (ICD-11):

- A. At least one of the following: A persistent and pervasive longing for the deceased or a persistent and pervasive preoccupation with the deceased.
- B. Examples for intense emotional pain: Accompanied by intense emotional pain (sadness, guilt, anger, denial, blame; difficulty accepting the death; feeling one has lost a part of one's self; an inability to experience positive mood; emotional numbness; difficulty in engaging with social or other activities.
- C. Time and impairment: Persistent for an abnormally long period of time (more than 6 months at the minimum) following the loss, clearly exceeding expected social, cultural or religious norms for the individual's culture and context. The disturbance causes significant impairment in personal, family, social, educational, occupational and other important areas of functioning.

***Ähnlichwerden I: Cleaning the sink* (Film, 33 seconds, June 2021)**



Wolfgang: *In conversation with Jill, June 2021. After I have shaved my beard, I routinely clean the bathroom sink with my right hand. I do not consciously think about this tidying up. It happens automatically. I was not really aware of this, until one morning in June 2021, what seemed to me like a routine turned out to be something more. Suddenly, I realize that I do it exactly the way I have seen my father doing it. As a young boy, I might have been nine or ten years old, I stood in the bathroom door and watched him shaving his beard and cleaning the sink afterwards. His gentle small motions as he wiped away the beard hairs and shaving foam from the white ceramic sink are very similar to mine. I recognize his movements with their pace, direction, sequence, naturalness in my own movements. I have cleaned the sink hundreds of times before in the same way, but it is only now that I realize that it is me in him, and him in me doing it.*

This recognition and remembering of something that one has seen before in another person is what the German philosopher Thomas Fuchs captures in the idea of *Ähnlichwerden*. Fuchs argues that we are in permanent interbodily, or intercorporeal, exchange with each other, without necessarily having to touch each other or even be in the same physical or temporal space. *Ähnlichwerden* is

an experience that carries the shape and form of previous interactions, a “past tint” that can lead us into “a state shimmering between now and before” (Fuchs, 78). Fuchs concludes that our capacity for *Ähnlichwerden* is the basic phenomenological foundation of human kinship. This relatedness to another is something we embody and exists beyond specific interactions in shared time and space. It is a trace we carry and that emerged in Wolfgang’s cleaning of the sink as well as in Jill’s experience of folding clothes like her mother did. It highlights a way of understanding how identities are entangled through interaction and exchange, collective body memories, relational rituals, and disturbed bodily repertoires.

***Ähnlichwerden II: Un-folding* (Silent film, 2 minutes 38 seconds, October 2022)**



Jill: In conversation with Wolfgang, August 2021. *The dementia was sudden and severe. Not at all like you read it should be – slowly creeping in, a gentle haze of misremembering. At the hospital the senior nurse told me couples often work together to mask its existence and progression, so that symptoms can be concealed for a while, but inevitably one day the mask slips away. On that day we felt the first loss, as the person who had taken care of everything suddenly disappeared. The second loss happened 5 months later when she died.*

The dementia was like a tornado ripping through our family as life went from the comfortable rhythms of daily togetherness to total chaos to tranquil emptiness. In the aftermath of this tornado there was a lot of tidying up to do. Existentially, metaphorically, and literally. That is how doing loss seemed to start – the sorting out, the taking stock, the reorganizing of the

Unfold: | ʌn'fəʊld | verb **1** open or spread out from a folded position: **2** [no object] (of events or information) gradually develop or be revealed: • [with object] reveal or disclose (thoughts or information):

Fold bend (something flexible and relatively flat) over on itself so that one part of it covers another: **2** [with adverbial] cover or wrap something in (a soft or flexible material): • hold or clasp (someone) in one's arms affectionately or passionately:

materials of mum's life, her things, and my own – feeling the entangling of the two.

Going through mum's wardrobes and drawers – sorting the clothes and folding the clothes.

Folding the clothes.

Folding the clothes.

An ordinary everyday ritual in an extraordinary time. It was comforting in its continuity and repetition. Yet, as I folded and straightened, turned and tucked each item, I recognized that my way of folding, of lining things up, laying things out was exactly like hers. Her way of folding clothes was something I had watched over and over growing up, later she taught me how to do it (I was really reluctant I remember, we argued because I wouldn't pay attention). I remember her telling me that her grandmother had taught her to fold clothes this way – properly, for less ironing. A real life skill. And now here it was, this was mum's way of doing it, and I had a new sense of knowing her, and me, in my every micro movement.

The experience of *Ähnlichwerden* turned out to be an embodied revitalization of the genuine relationship and intercorporeal exchange with our parents. Throughout our lives, and even now, after they had passed away. In his work, Fuchs points out the difference between explicit and implicit corporeal memory. With our explicit memory, we remember a specific situation experienced in the past and recall it as such. Examples might include the recipe for a cake, our wedding day, or the telephone number of an old friend. On the contrary, implicit memory refers to intercorporeal phenomena, and the

formation of individual patterns and habits of perception and movement that evolve through repeated interaction with others over time. *Ähnlichwerden* is a mimetic experience and originates from corporeal memory: *how* we fold clothes, *how* we shave and clean the sink afterwards. While the explicit, autobiographical memory represents the past only as the past, the corporeal memory conveys the vivid present of the past.

The lifelong malleability of body memory enables the formation and transformation of habits, structures of perception and action. This allows assimilation to the respective natural and cultural environment, rooting and home in the social space. On the other hand, the structures anchored in body memory are the basis of the continuity of our selfhood. Habit turns us into people with a certain constancy and reliability, it lets us remain the same despite all external changes. Everything we call personal identity, personality, character is based on our corporeal acquaintance with ourself, on our bodily/corporeal memory. (Fuchs, 6)

Ähnlichwerden contains both the experience of familiarity and coherence, and the capacity for transformation and change. We have both developed our embodied knowledge over a lifetime together with our parents. It is not how we make meaning of cleaning the sink or folding clothes as part of our grief work. Rather, it is the meaning held in the act of doing it that is comforting as it is a vivid feature that does “not present the past but contains it as presently active. It does not lead back to the past, but on the contrary means the possibility of turning to a new present” (Fuchs, 72). In this sense, we experienced *Ähnlichwerden* as hopeful and comforting. However, we imagine that such experiences can also be challenging as they carry the realization of loss with them, and even might elicit adverse feelings if one does not like to show similar behavior or detects disagreeable character attributes from the other person in oneself.

Here on the sofa (Poem, 13th February 2021)

I cannot see you. I cannot hear you anymore
But I sense your presence
Magnetic, overwhelming, comforting
Have you been waiting for me? Did you stay with her until I arrived?
You are still there. Here on the sofa. I sense your presence. You are not gone

The liminal space of what is and what is no longer
The niche between here and there
Life and death
There you have been waiting for me
To embrace each other for the last time.

None of us is left alone. You are still here. On the sofa
In presence. In resonance. In concord. In transition.

Wolfgang in a conversation with Jill, October 2022: *I feel this poem is one of the most intimate pieces that I contributed to our dialogue. At first, I was a bit hesitant to share it, probably because it is difficult to find words for this experience. Actually, it is beyond what I have words for, but at the same time it is a most intense experience of transition and relatedness. It conserves a moment of realization that is core to my response to the loss. I think the form of a poem works best to tell and share this moment when I realize that he is still there, with us – but where his death also becomes certainty. I was not just an observer of this scene, but in the very middle of it... a kind of split awareness of being part of it and at the same time wondering what was going on. I guess that is why it is so difficult to articulate, words seem superfluous. It is a felt sense. It is an embodied, transformational experience that defies words or explanation. Now, more than one and a half years later, I still wonder how this intense meeting with him could happen and how long it lasted. Was it 30 seconds? Less? More?*

Doppelganger (Audio piece, 4 minutes 40 seconds, April 2021)

Wolfgang: *In April 2021, two months after the funeral, my partner and I spent a weekend at the cabin which is close to the Fjord. It was a stormy Saturday afternoon, when we went for a short walk along the shore. The wind was so strong that we had to lean against it and work our way through it. However, that day, its strength and physical materiality felt almost liberating to me. I got the idea of the wind as an imaginative sparring partner, a monumental punch bag that I could measure my strength against, that could take my hits, absorb them, make them less painful and threatening. I started to sing. Without text. An expression of mourning. I climbed up a rock to expose myself to even more of the wind's energy and power. To counter nature's power with my song – a simple lamenting motif that I repeated. It was both singing against and with the wind. Feeling response and feeling contained in its bluster. I felt that there was the virtue of a prayer in it, where I could bewail my loss, find a valve for my strain and inner turmoil. After a while I recorded the song with my mobile.*

Jill: 12th April 2021: *Wolfgang tells me about his recording from the fjord, and I ask him to send it to me. I listen with headphones. The audio crackles and hisses – the sound of the wind overwhelms the microphone and distorts the sound. I hear Wolfgang's vocalizing often overwhelmed by the roaring sound of the blast. Yet, the voice manages to resist. The voice stands up against the blast.*

This is the sound from the center of the grief storm – I resonate with how it feels, overwhelmed and small. It reminds me of how my own grieving process has repositioned me as my mother's child, regardless of how much I age. To be a child is more than being a minor or under 18. Being someone's child defines us relationally whether the relationship was close or distant. All the terminology I can think of to define or describe the child in me is negative, problematizing, pathological. I realize I need another word for this adult child in me.

The more I listen the more I hear different qualities in the voice: anger and control. I hear different qualities in the wind. It's the sound of the force that can hold a person up as well as knock them down. I had to respond by adding to the sound, by putting myself in the grief storm. I immerse myself in listening, taking the melody, filtering the sound to place the lamenting voice more centrally. I deconstruct and rerecord different layers, processing the sound as I go.

As I work on the piece a new feeling emerges, something strange and uncanny. Working on this musical expression allows me to get lost in the grief storm again, and for some moments I don't feel at all myself, I am looking down on myself from a distance—an uncanny stranger in my own body. Sat at my desk, in front of the all-consuming screen, I cry. A lamentation. No one sees or hears, a secret mourning with all its weirdness and dark feelings.

Sobbing, crying, weeping, howling –
grieving is a deeply embodied process,
and the ancient genre of the lament
reflects the profound bodily need to
voice grief in visceral and fleshy ways.
(Lykke, 199)

Wolfgang: 17th April 2021: *Jill has composed a piece of music with and around my lament from last weekend. This is really touching. It feels like an enactment of understanding and transformation of an experience we both know. The piece is 4 minutes and 40 seconds long. It has three parts and starts with my lament played on the piano. The simple melody played in the middle register of the instrument fades into the original soundtrack from the cabin recorded with my mobile phone. The sound of my voice and wind are supplemented by energetic, vortical steel drum-playing. The sound of the steel drum is raw and metallic. It embeds my singing and the wind and at the same time increases the music's power and intensity. It almost transforms my ideas to an expression of strength that both gives comfort and shows the enormous vulnerability that I felt. The third part of the piece is a polyphonic, canon-like vocalization sung by female voices in a higher register without a text. They repeat a short motif*

and create an otherworldly atmosphere. In a conversation on zoom, Jill suggests Doppelganger as the title for this co-created piece. She talks about Alphonse Daudet, the nineteenth-century novelist that she had recently read about. Daudet lived with excruciating stigma and pain due to syphilis and was always searching for what he called “my doppelganger in pain”, a person whose disease most closely resembled his own (Biro, 19). The analogy of the Doppelganger, of fellow sufferers who can sympathize with each other and mirror feelings takes shape in our joint composition. The music contains and relieves some of the pain that is beyond words and comfort.

***Lost in regret* (Film with audio, 4 minutes 40 seconds, December 2022)**



I should have, I should have, I should have

regret (verb)

Late 14c., *regreten*, "to look back with distress or sorrowful longing; to grieve for one, remembering," from Old French *regreter* "long after, bewail, lament someone's death; ask the help of" (Modern French *regretter*), from *re-*, intensive prefix (see *re-*), + *-greter*, which is possibly from Frankish or some other Germanic source (compare Old English *grætan* "to weep;" Old Norse *grata* "to weep, groan"), from Proto-Germanic **gretan* "weep."

From 1550s as "to grieve at (an event, action, revelation of facts, etc.)." Related: *Regretted*; *regretting*. 1530s, "complaint, lament," a sense now obsolete, from the verb, or from French *regret*, back-formation from *regreter* "long after, bewail" (see *regret* (v.)).

From 1590s as "pain or distress in the mind due to some external circumstances" (as in *to look on (something) with regret*); 1640s as "pain or distress in the mind at something done or left undone." In correspondence, in declining an invitation, etc., **regrets** "expressions of regret, intimation of regret for inability to do something" is attested by 1851.

Walking with Loss (Photographs/text, 26th February– 9th March 2021)



Jill: *It's the day after the funeral.*

Day 1. What to do? What to do on a day like this? When loss becomes our everyday and life just goes on. How to get through it? It is only 8.00 am. I don't recognize this new feeling, this new way of being in the world. I feel heavy – exhausted.

I don't remember who suggested we should go to the beach – was it me? We just knew it was the only thing to do.

So we went, just the two of us. The usually boring car journey felt reassuring, allowing us to be out in the world but also totally isolated from it. Just she and I encased in a vehicle for our thoughts. When we arrived at the beach the weather was strange – an unusually mild day,

completely still in a place renowned for its turbulent winds, rain, and biting cold.

We walked. Listening to the sea. Nothing was said as we collected pebbles and wrote her name in the sand and then watched as the sea gradually washed it away. This action seemed to give a new meaning to the thoughts about letting go, letting her be taken from us back into the world. We remain her daughters. This interdependence is indelible even when we can no longer talk, or touch or see each other – we are bonded, the relationality is embodied, engrained, incorporated.

Today she moved with us.

And we learnt to walk again

Wolfgang: *It is the morning after the funeral – a fairly blue and sunny sky for February. Before I go to the airport and back to Norway, I feel the need for a last walk in the forest and fields close to my home place. The beech forest where we have been together so many times. The fields where my family and I went for cross-country skiing. Where my brothers and I carried each other on sleighs, chasing each other, laughing, out of breath. Where we were looking for squirrels and birds, looking for Easter eggs that he had hidden for us in the moss at the tree stumps. On cold and sunny days like today.*



All was ours.

Our place. Our little world.

Freedom. Joy. Love. Inviolable. Belonging.

The trees are still there.

Grown-ups now. Bald and covered with snow.

I will be back to see them come into leaf.

Staying with loss—Integrating loss?

In this paper, we ask how the experience of loss and mourning can be articulated and shared. We found that arts-based work and materials provide important ways of speaking about these existential, relational, and transitional issues that often exceed language and comprehension, and that can be silenced or stigmatized. Following Nina Lykke’s example, we created poems, took photographs, and shared notes from our diaries, to acknowledge ways of doing and coping with our own loss. Over the course of two years, we developed an everyday repertoire of artistic responses and actions to express and share our

mourning. Like process, we with layered narratives, and often circling

Sometimes the best comfort can come from knowing you are not alone in your grief— that others have felt as you do, whether you find them through support groups, literature or in your own existing circle. To know this is not to gain comfort by removing the ache, but to help us to feel less alone in the midst of aching (Schillace, 196).

any creative arts worked intuitively, rather than linear sometimes chaotic back on themselves.

We did not follow a predetermined order or logic through any stages of grief and we do not suggest a standardized or solution focused approach to mourning by simply turning to the arts. The tendency to instrumentalize arts-based work to accelerate or complete processes of mourning merely adds to the pressures to deny mourning that we seek to challenge with our work. Rather, the artistic fragments both reflect and contain our mourning with its tensions and complexity. The fragments provide spaces that might invite people to engage, resonate, or disagree, and in doing so tell their own stories. They might invite people to value and use the arts themselves, to write a poem or short story, to

listen or dance to music, to sing or hum, to look at a painting or explore drawing.

Our approach resonates with newer bereavement theories that characterize a person's mourning through the dynamic shifts between accepting one's loss and at the same time fighting against it (Hall; Neimeyer). By not masking sad experiences with nice art work, nor detaching from those who have died, but rather by searching for and celebrating new and continued bonds with the deceased (Klass et al.; Neimeyer et al.). These relational and transitional processes change over time and should not necessarily be deemed pathological or seen as simply reminiscences about the dead. Rather, they are a *re-membering*, by which the deceased can regain active membership in their loved ones' lives (Hedtke and Winslade). As Blake Paxton, grieving his mother for more than ten years shows with his autoethnographic account *At home with grief* (2018), communal and everyday subjective experiences of the continuing bonds and *re-membering* of the deceased challenge cultural prescriptions for mourning. These experiences may help us to acknowledge how a person's relationship with their grief changes in the long term and may help maintain or restore our bonds with the living.

Death ends a life—not necessarily its relationships. In this sense, we understand our arts-based work as an attempt to endure and handle the tensions, silences, and contradictions that arise from bereavement, and as relational and transitional practices that help us to gain orientation and build new relationships over time.

Mournability: What death tells us about life

The finite span of our lives makes dying and loss an inevitable part of life. For middle-aged adults grieving parents who have lived a long life, specific societal taboos around mourning are clear, as is the pressure to move on quickly and not linger in grief. There seems an implicit sense that the degree of loss should be less painful, that the inevitability of the loss, added to the maturity of the middle-aged, makes this the most bearable of losses; certainly for many there is comfort to be taken in the passing of someone who has lived beyond their medically defined life expectancy. But the way society views the mourning of the old reveals much about which lives a society values most, because how we understand and respond to death is closely tied to the ways in which we value and understand life (Butler; Schillace). In some cultures, there are examples of very different ways of mourning elders, particularly parents, for example, in Confucianism there are five grades of mourning, with the death of a parent meriting the longest period of mourning of 27 months. Butler's important work on the hierarchy of *mournability of life*, the way we accept that some lives are *less mournable* than others, has serious consequences for those whose lives we accept as less worthy of mourning, and for those who mourn for them. Butler notes: "If certain lives are considered not worth grieving, then it becomes easier to inflict injury upon them, to allow them to be lost, to permit their dehumanization and exploitation" (Butler, 20). Although Butler writes about how lives are devalued based on their sexuality, gender, or race, we may ask, how does age affect the mournability of a life? We would argue that mourning the old is important not only for the ways it illuminates personal or relational experiences, but also for what mourning tells us about how even

Grief is not a private affair; it is a social and political act, an act that testifies to the tie that binds one to another, an act that insists upon the recognition of commonality, an act that seeks to repair the world by acknowledging its fundamental fragility and dependence. (Butler, 4).

personal grief can be profoundly shaped by social situatedness and political processes.

Sociologist Les Back reminds us that contemporary Western culture is one that speaks rather than listens. He asks how we might listen more carefully, concluding that the *art of listening* to complex experiences is founded in humility and care. The starting point for our work on grief was to focus on ways of *hearing loss*, foregrounding how listening affords spaces where different forms of expression and understanding are possible. The ability to *hear loss* is an important tool for both the *mourning I* and the *mourning we*, as such compassionate acts of listening deepen recognition of our fundamental relatedness. *Hearing loss* is a way of acknowledging experiences of mourning through a relational practice that connects us to those who grieve and those who have died, regardless of whether we knew the deceased directly. It is perhaps through this kind of listening practice that stories may be more easily shared. In this way *hearing loss* offers a way of orientating ourselves towards death in life in ways that may can bring us closer to recognizing the mournability of every life.

WORKS CITED

- Biro, David, "When language runs dry. Pain, the imagination, and metaphor." *Dimensions of pain. Humanities and social science perspectives*, edited by Lisa Folkmarson Käll, Routledge, 2013, pp. 13-26.
- Back, Les. *The art of listening*. Berg, 2007.
- Butler, Judith. *Precarious life: The powers of mourning and violence*. Verso, 2004.
- Davidson, Jane and Sandra Garrido. *Music and Mourning*. Routledge, 2016.
- Eisma, Maarten, et al. "ICD11- Prolonged Grief Disorder Criteria: Turning Challenges Into Opportunities With Multiverse Analyses. *Frontiers in Psychiatry*, vol. 11, 2020, 752. Doi: 10.3389/fpsyt.2020.00752.

- Fuchs, Thomas. "Das Gedächtnis des Leibes." *Phänomenologische Forschungen*, vol. 5, no. 1, 2000, pp. 71- 89.
- Hall, Christopher. "Bereavement theory: recent developments in our understanding of grief and bereavement." *Bereavement Care*, vol. 33, no. 1, 2014, pp. 7-12. Doi: 10.1080/02682621.2014.902610.
- Halstead, Jill and Wolfgang Schmid. Anatomy of loss, The Research Catalogue: International Database for Artistic Research, 2023. Available at <https://www.researchcatalogue.net/profile/show-exposition?exposition=1712229>.
- Hedtke, Lorraine and John Windslade. *Remembering lives: Conversations with the dying and the bereaved*. Baywood Publishing Co., 2004.
- Kemp, Amanda. "This black body in question". *The ends of performance*, edited by Peggy Phelan and Jill Lance, New York University Press, 1998.
- Klass, Dennis, et a. *Continuing bonds: new understandings of grief*. Taylor & Francis, 1996.
- Knill, Paolo, et al. *Minstrels of Soul: Intermodal Expressive Therapy*. EGS Press, 1995.
- Onyeaka, Helen, et al. COVID-19 pandemic: A review of the global lockdown and its far-reaching effects. *Science Progress*, vol. 104, no. 2, 2021, pp. 1–18. Doi: 10.1177/00368504211019854.
- Paxton, Blake. *At home with grief. Continued bonds with the deceased*. Routledge, 2018.
- Lykke, Nina. *Vibrant Death: A Posthuman Phenomenology of Mourning*. Bloomsbury Publishing, 2022.
- Neimeyer, Robert. *Techniques of grief therapy: creative practices for counseling the bereaved*. Routledge, 2013.
- Neimeyer, Robert, et al. "A Social Constructionist Account of Grief: Loss and the Narration of Meaning." *Death Studies*, vol. 38, no. 8, 2014, pp. 485-498. Doi: 10.1080/07481187.2014.913454.
- Reckwitz, Andreas. "Auf dem Weg zu einer Soziologie des Verlusts". *Soziopolis: Gesellschaft beobachten*, 2021. <https://nbn-resolving.org/urn:nbn:de:0168-ssoar-80750-2>.
- Sallnow, Libby, et al. "Report of the Lancet Commission on the Value of Death: bringing death back into life." *Lancet* vol. 399, 2022, pp. 837-84. Doi: 10.1016/S0140-6736(21)02314-X.
- Schillace, Brandy. *Death's Summer Coat. What the History of Death and Dying Can Tell Us about Life and Living*. Simon and Schuster, 2017.
- World Health Organisation. WHO COVID-19 dashbord. <https://data.who.int/dashboards/covid19/cases?n=c>.

Jill Halstead is a Professor of Music at the Grieg Academy, University of Bergen, and leader of the Grieg Research School in Interdisciplinary Music Studies, a research consortium of five universities on the west coast of Norway. Recent creative work includes composing music for film and dance theatre works

which explore the stigmatization of aging and dis/ability. Between 2018-2022 she led the artistic project *Social Acoustics: Sound, Body, Community*, with Prof Brandon LaBelle, a project which explored listening as a social practice. She currently leads *Music4Change*, an EU funded transnational cooperation partnership focused on questions of social and environmental sustainability in music research and education.

Wolfgang Schmid is a musician and music therapist, and Professor of Music Therapy at the Grieg Academy, Faculty of Fine Art, Music and Design at the University of Bergen in Norway. He holds a part-time position as music therapist working with dying people and their families. Wolfgang has many years of experience as music therapy practitioner-researcher in interdisciplinary intensive and palliative care, with autistic children and persons with dementia. His research interests span from the study of intercorporeality and embodied listening in music improvisation, to experimenting with qualitative and arts-based approaches. From 2019-2023 he was Co-Investigator in the AHRC-funded international ethnography *Care for music*. Currently he leads the project *IMAGINE – envisioning care at the end of life from an experts by experience perspective*.