

# 'THE SHAPELESS GHOST'

## *Ambiguous Loss and Creativity in Learning How to Breathe*

*This paper explores the representation of ambiguous loss in a recent Australian memoir, Learning how to breathe by Linda Neil (2009). My reading of this memoir focuses on the way presence and absence are manifested in the text and the way acts of creativity—making music, recreating family history and writing the memoir—are invoked as a way of tolerating ambiguity and reconfiguring the narrator's sense of identity. I suggest that memoirs about ambiguous loss give an important voice to an otherwise silenced, though common, form of grief.*

---

Keywords: ambiguous loss—grief—life writing—memoir—creativity

That feeling of nearness to the shapeless ghost, Ambiguity, is what I want most, what I want to put inside a book, what I want the reader to sense. And because it is at once a thing and a no-thing, the reader will have to find it, not only in what I have written, but also in what I have not written. (Hustvedt 2012: 23)

Siri Hustvedt is here describing the allure of ambiguity in literature and how it resists category—its formlessness. Her understanding of ambiguity embraces both the concept of two possible ways and of obscurity or doubt. It is both presence and absence. This description of ambiguity and the term 'shapeless ghost' struck me forcefully because they would be equally applicable, I think, to the representation of grief in life writing literature. So many autobiographical works seem to arise from the shadow of grief, and yet it often remains a shifting, formless thing within a text, an absence as much as a presence. Thinking of the relationship between grief and ambiguity has led me to explore the way memoirists represent ambiguous loss in their texts and how these representations may be interpreted.

This paper explores the representation of ambiguous loss in a recent Australian memoir, *Learning how to breathe* by Linda Neil (2009). My reading of this memoir focuses on the way presence and absence are manifested in the text and the way acts of creativity—making music, recreating family history and writing the memoir—are invoked as a way of tolerating ambiguity and reconfiguring the narrator's sense of identity.

The theory of ambiguous loss was developed by researcher and family therapist Pauline Boss and became well known after the publication of her 1999 book *Ambiguous Loss*. Since then, Boss and others have extended her theory and developed a therapeutic approach or set of guidelines for working with ambiguous loss. Boss argues that presence and absence are not absolutes, and that it is the ambiguity between presence and absence that creates a kind of loss that complicates grief, confuses relationships and prevents closure. Ambiguous loss can be viewed as a type of complicated, non-finite or unresolved loss, but the work that Boss and others have done on ambiguous loss locates the unresolved aspect of

the loss, not in the individual griever (as in many theories of complicated grief, a legacy from Freud's notion of melancholy versus mourning) but in the situation itself.

There are two types of ambiguous loss. The first is where a loved one is physically missing but psychologically present. For example, if someone is missing in war, at sea, as a result of kidnapping, terrorism or natural disaster, the family will experience ambiguous loss: the individual is physically absent, perhaps dead, but there is no evidence of this death, no death rituals and no certainty. Their status as alive or dead is unknown and therefore they are kept psychologically present. This type of loss has been described as 'leaving without good-bye' (Boss 2007).

The second type of ambiguous loss has been described as 'good-bye without leaving' (Boss 2007). This is where someone is physically present but psychologically absent or changed. For example, individuals with dementia, brain injury or other cognitive or emotional disabilities are psychologically absent or changed and yet their families still live with and usually care for them: they are very much physically present. Other examples of this might be people with addictions or alcoholism, or who are so psychologically and emotionally damaged that they aren't available for connection with their loved ones. This is the type of loss evident in Neil's *Learning how to breathe*.

Boss argues that the very ambiguity of these types of losses is what makes them so stressful. The normal beginning (and, often, ending) of mourning is not available. Finding sense and meaning in a situation that appears to defy logic and resolution is very difficult, and may result in high anxiety, emotional paralysis and stress. Carolyn Feigelson refers to Freud's notion of the uncanny and suggests that ambiguous loss is an 'uncanny union of opposites' (1993: 331). She argues that something unknown amalgamates with something known to produce an uncanny sensation: 'The anxiety of the uncanny involves something on the border of what we both know and don't know, both cognitively murky and affectively alarming' (1993: 331).

The therapeutic approach in this theory of grief is not about closure (as in some phase models of grief) nor does this theory view unresolved grief as pathological. Rather, the goal of therapy here is to identify and recognise the ambiguity of the loss, and to increase the individual's tolerance of ambiguity. Boss argues that the most important predictor for resilience in the face of ambiguous loss is an individual's ability to learn how to hold two opposing ideas in their minds at the same time. For example, a wife may have to recognise that her husband is still living with her but is also gone (because his dementia has changed him so much he is no longer her husband in the same way). Living with this type of contradiction will often result in ambivalent feelings: for example, both loving and hating the husband who is no longer your life partner in the same way. Such a situation may also result in profound confusion over the roles, status and boundaries within families or friendships; individuals will often have to hold onto multiple identities and roles: for example, wife *and* carer. Boss argues that individuals who are experiencing ambiguous loss need to reconstruct their identity and suggests that narrative therapy is one of the most effective tools for doing this.

The theory of ambiguous loss has been developed over a period in which other new approaches and theories of loss and grief have also developed. As Bruce and Schultz suggest, 'in literature and in practice there has been a tendency to rely on the theoretical paradigms specific to death and dying to explain grief responses in general' (2001: 32). However, new theories and models of grief have emerged over the past decade, questioning the assumption that the bereavement experience is necessarily the prototypical grief experience. These new theories argue for a more complex understanding of grief, and move away from 'stages' through which all griever must progress towards an understanding of the role gender, culture, past experiences, childhood attachments and other personal characteristics have to play

in the grieving process (eg Attig 2001; Hooyman & Kramer 2006; Neimeyer 2001). These new approaches, like Boss' therapeutic approach to ambiguous loss, focus less on 'acceptance' as an end point of the grief process and more on the role of grief in redefining the self and the task of accommodating loss within one's new identity.

Alongside these new approaches in psychology and the social sciences, has been a development within literary and cultural studies of what Forter describes as poststructuralist explorations of a 'melancholic subjectivity' (2003: 137). Scholars such as Santner (1990), Ramazani (1994), Novak (1999) and Moon (1995) suggest that Freud's notion of melancholy as abnormal grief and mourning as normal grief pathologises the experiences of certain groups, such as people of colour, non-heterosexuals and other disempowered groups. Kristeva also explores this terrain in *Black Sun* (1989). While Kristeva and others discuss ambivalence in grieving (usually in the context of the love/hate relationship the griever has with the person lost), they do not explore the particular predicament described by Boss: the practical experience of loss that this is both a loss and not a loss.

It is by using Boss' theory of ambiguous loss as a frame that I analyse the way ambiguous loss is represented in *Learning how to breathe* by Linda Neil. Published in 2009, the book describes how Neil returns to Brisbane to look after her mother in what turns out to be her final illness, an initially undiagnosed dementia and Parkinson's disease.

Neil starts her book like this:

Two things happen today. My mother falls and I foresee my own death. These two things may or may not be connected. My mother's falling precipitates a moment of clarity in which I know that through her falling I will be changed forever. I know as I watch her fall that, contrary to the habit of a lifetime, I will not walk away. I will not disengage myself from her falling and by engaging in her fall I will fall myself. (1)

In this way, Neil foreshadows the trajectory of her memoir about her mother's failing health, her own increasing role in caring for her mother, how it unravelled her and how she has reconstructed herself as a deeply engaged and connected family member. At one level, the memoir is a chronological story of Neil's return to Brisbane to see her mother, her mother's increasing confusion and illness, Neil's struggle with the medical profession to get proper care for her mother, an eventual diagnosis of Parkinson's disease and, finally, Neil handing over day-to-day care of her mother to one of her brothers. The deeper story, however, is the tale of Neil's reconnection with her family after years of travelling, and the consequent reconfiguration of her own identity as musician, daughter and sister. Kathleen Fowler points out that 'one central theme regularly recurs in the grief memoir—the sense of finding oneself navigating uncharted territory' (2007: 528). Tom Couser says of family stories about Alzheimer's: 'the complex renegotiation of family dynamics and the relational (re)construction of identity in these fraught circumstances are at the heart of the best of Alzheimer's narratives' (2009: 228). While not being a grief memoir or Alzheimer's memoir as such, Neil's book does reflect the sense of being in uncharted territory, the renegotiation of family roles and the reconstruction of identity. Like many writers of filial memoirs, Neil explores her current relationship with her mother by revisiting her own childhood memories and researching and reconstructing her parents' lives. Even though the book is ostensibly about her mother, Neil also spends a considerable time revisiting her relationship with her father, Ben, who died in 1993, five years before Neil's mother, Joan, becomes ill.

Joan was a singer and a singing and piano teacher and her children were encouraged to develop their musical talents. Neil herself is a singer and musician, having travelled the world with her violin,

composing her own music and living what she describes as a wild 'gypsy life'. This ceased when her brother called her and said their mother 'might need some help'. Neil uses this family love of music as a connecting thread in her memoir, particularly focusing on the way singers must learn to breathe. More than this, she suggests that it was only through music that she really knew her mother.

I can't really say I ever knew my mother ... Not on the inside ... I only ever sensed her through the soundtrack she provided for my life, from the past to the present, from the songs she sang around me when I was a child to the songs I wrote myself and sang to her when I returned to care for her and the disease which eventually will claim her voice, the only thing about my mother I ever really knew. (50-51)

After a year of illness, Neil describes a 'musical soundtrack imploding' in her mother's brain: 'I listen and listen in the silence that grows around her, but all I can hear are her sighs, the soundtrack, now, of her loss' (72). As if to try and know her mother better or to revive the sound of her childhood mother, she quotes from Joan's articles on singing published by the Music Teachers' Association of Queensland in their newsletter, and interviews her siblings, including quotes and dialogues from the interviews in her book. She continually returns to Joan's musical achievements and her own musical life, counterpointing Joan's gradual decline with memories of her vibrant singing and teaching.

In this way, Neil dramatises the presence and absence of ambiguous loss. As her mother becomes more confused, has psychotic episodes, and then suffers increasing physical frailty and paralysis, Neil recreates more vividly Joan's musical life, her legacy to her students and to her children. Her mother's increasing absence in life is contradicted by her greater presence in memory. The less her mother is able to communicate, the more Neil introduces the voices of her older siblings and their memories and stories. Struggling with the ambiguity of her situation, Neil both embraces it and balances it through her work as family chronicler. She is aware of the fact that she turns to music 'in times of crisis or uncertainty' (18). Paradoxically, while the musical life she chose during the 1990s—the wild gypsy life of improvisation and street music—initially confounded her mother's expectations for her of a classical musical career and distanced her from her family, after her mother's illness it is this life that has in some way prepared her for the next few years of uncertainty and the unknown trajectory of Joan's health. Neil's own partial absence from the family for some years has freed her to become more present just when the family need her. Her adoption of a creative life, as musician, has given her a key to how she can navigate the difficulties of coping with her mother's illness. By recreating the family's musical lineage through a patchwork of texts, memories and stories, she is using her creative process to understand and manage the emotional pressures of illness and the caring role.

I read the purpose of Neil's family research, then, as partly an effort to manage the ambiguity of coexisting presence and absence and partly to reconstruct her own identity as musician and family member. Boss notes that ambiguous loss requires 'cognitive and emotional reconstruction of roles, status, boundaries and rituals' (2006: 115). The complexities around this relate to the lack of clarity in these roles, holding multiple roles and the contrast between expected and actual roles. For Neil, there is a shift from distanced daughter—'It has been a long time since I have done anything a good daughter or a good sister might do' (10)—to being the key family member responsible for her mother's care. Like most children of ageing or ill parents, Neil finds this dual role of daughter and carer confusing. She also experiences stress around the expectations she believes the medical establishment has of her—that is, to be grateful and humble and follow advice—as against her own desire to ask questions and debate care options. In her shifts from wild daughter to primary caregiver and from submission to rebellion over conventional medical approaches, Neil initially holds what could be described as an 'either/or' perspective. But by the end of the book, she has moved towards what might be described as 'both/and'

thinking. She can both pursue her own musical career and help care for her mother. She can both accept and reject the conventional western medical paradigm. This move to dialectical thinking is one way for individuals experiencing ambiguous loss to reconceptualise their lives.

Music gives Neil a way to realise these changes in her role and identity, as well as a way to ritualise her new status. The final pages of the book show her singing to her mother, inviting her mother to sing along, even though Joan can hardly even hum. The book ends with Neil lying next to her mother on the bed, a photograph of Neil's father within sight and other family members within hearing and Neil's violin 'full with song' lying beside them both.

Much of the discussion of music in this book is around mastery and the idea that one can attain mastery of an instrument or one's voice through skills development, coaching and hard work. In a seeming contradiction, these stories of mastery are countered by the opposite—the gradual failing of Joan's cognitive and physical functioning, including her ability to sing. This echoes Boss' suggestion that living with ambiguity requires us to moderate our desire for mastery. Because the ambiguity of the lived experience cannot be resolved through mastery, Boss argues that to live well in such situations individuals need to recognise that they cannot live their life in the way they want and must accept an imperfect situation. For all the discussions in this book about mastery, there is also an acceptance of limitations. Joan achieved much in her career but not the full recognition that Neil and others feel she should have had. And Neil is constantly renegotiating the balance of work and family in her life, and her goals for composition and performance.

Alongside the musical memories, of course, are the medical events. Like many patients and carers, Neil struggles with the inability of doctors to diagnose and then manage her mother's condition. When the prescribed medications cause Joan extreme distress or result in psychotic behaviour, Neil is furious but impotent. The medical paradigm that requires illness to be mastered has failed her and she realises that she needs to move on from the idea that Joan can be cured. With the recognition that her mother will not recover and will need full time care comes a re-negotiation of the attachment between mother and daughter. Neil has become much closer to her mother through her caring role but she must start the journey of gradual disconnection from her mother while reconnecting with others. Initially, Neil rejects several male partners because she feels she can't make a commitment to a lover as well as to her mother. Near the end of the book, after Neil has had a year travelling overseas while her brother cares for Joan, she becomes reconciled to the idea of committed love. She says:

I had spent a lot of time trying to get over love, get through love, or forget about love. To wait for love, and the fierceness in my heart, to die so I could move on. It is useless to think that love dies. I understand at this moment, though, that it can change and that music can help to bring about that change. (335)

She also remembers her mother's advice that if she wants to live a passionate life she must 'know how to keep breathing' (340). Neil returns again and again to the notion of learning to breathe, the idea that one must *learn* how to love and how to live well. She notes:

It would take an illness and a homecoming for me to know my mother; and even further on, it would take the writing of a book, and the gathering of a hundred stories and memories, for me to know my father. (343)

Through her creative work writing about her parents, Neil has re-made herself from the shattering that happened when she encountered the complexities and losses around Joan's illness. This is not to say

that *Learning how to breathe* is a simple recovery or redemption memoir. Certainly the project of the book is for Neil to explore and understand herself in the context of her mother's illness and her own role within the family. However, the book does not conform to the self-help narrative arc of tragedy-to-triumph or loss-to-recovery. At the end of the book, nine years after the start, Neil's mother is still alive, though unable to do anything for herself. There is no resolution of Joan's illness or the family's feelings of grief around her.

In reading this work through the lens of ambiguous loss theory, I have focused on the ambiguous loss a daughter experiences when her mother is both present and absent through illness. However, for many adult children, the experience of ambiguous loss starts before their parents age, and Neil is no exception. To some degree, her relationship with both her parents as a young child was one of presence and absence. She felt disengaged from her parents, as though they were not available to her. Her father, having previously been a priest, was loving but not easy to relate to and her mother seemed unemotional and distant at times. Neil's situation reminds me in particular of Sue Miller's feelings about her father described in *The story of my father* (2003). Miller says that she realised that her father never had the kind of 'self-conscious self' that most of us have; he was more 'abstract'. When he got Alzheimer's disease, he seemed to suffer less from the loss of self or ego than many other people do. Miller realises that 'his Alzheimer's disease in a sense merely exacerbated a lifelong feeling of loss I had about my father. *My father was not his own*. Therefore he couldn't be anyone else's—and he wasn't' (2003: 165, emphasis in original). She describes him as an 'abstract father. A father who might forget you if what he was thinking about at the moment was more compelling to him' (2003: 165). This sense of having a partially absent or 'abstract' father (and sometimes mother) is a story often repeated in the filial memoirs of contemporary midlife and baby boomer writers. As their parents age, these writers are telling a doubled story about ambiguous loss, reflecting another permutation of the *doppelgänger* effect of the familiar/unfamiliar paradox of ambiguous loss narratives.

I have approached that 'shapeless ghost', ambiguity, in a text that is also about creativity, grief and personal identity, getting nearer but never able to capture its exact contours. What is the value, then, of reading memoirs that tell of such a formless and shifting type of loss? Boss argues, 'Ambiguous loss is inherently traumatic because the inability to resolve the situation causes pain, confusion, shock, distress, and often immobilisation. Without closure, the trauma of this unique kind of loss becomes chronic' (2006: 4). There is strong evidence that one of the key determinants of people's ability to cope with grief and loss is their ability to make a meaning-based story about themselves that helps to integrate or accommodate the loss within their life. Other people's stories are essential in this process. Arthur Frank, speaking of illness survivors and their need for story notes, 'Stories need more than events or evidence of events; stories are formed from other stories' (2009: 186). Memoirs like *Learning how to breathe* give those experiencing loss, access to stories that will help them construct their own revised identity narratives. They provide a counter to society's expectations that grief is a linear process consisting of expected stages or phases and that only certain types of grief constitute legitimate losses. Writing and publishing a book about ambiguous loss reverses the usual silencing of this type of non-standard loss. As Hustvedt says, 'there is no diagram for ambiguity, no stable alphabet, no arithmetic' (2012: 22). Instead, there are stories.

---

## WORKS CITED:

Attig, Thomas 2001 'Relearning the world: making and finding meanings' in Robert A Neimeyer (ed),

- Meaning reconstruction and the experience of loss*, Washington DC: American Psychological Association, 33-53
- Boss, Pauline 1999 *Ambiguous loss*, Cambridge, MA: Harvard University Press
- Boss, Pauline 2006. *Loss, trauma, and resilience: therapeutic work with ambiguous loss*, New York: Norton
- Boss, Pauline 2007 'Ambiguous loss theory: challenges for scholars and practitioners', *Family relations* 56 (April): 105-11
- Bruce, Elizabeth and Cynthia Schultz 2001 *Nonfinite loss and grief*, Sydney: MacLennan & Petty
- Couser, G Thomas, 2009 'Memoir and (lack of) memory: filial narratives of paternal dementia', in Christopher Stuart and Stephanie Tod (eds), *New essays on life writing and the body*, Newcastle: Cambridge Scholars Publishing, 223-40
- Feigelson, C 1993 'Personality death, object loss and the uncanny', *International journal of psychoanalysis* 74.2 (1993): 331-45
- Forster, Greg 2003 'Against melancholia: contemporary mourning theory, Fitzgerald's *The Great Gatsby*, and the politics of unfinished grief', *differences: a journal of feminist cultural studies* 14.2 (Summer): 134-70
- Fowler, Kathleen 2007 "'So new, so new": art and heart in women's grief memoirs', *Women's studies* 36.7: 525-49
- Frank, Arthur W 2009 'Tricksters and truth tellers: narrating illness in an age of authenticity and appropriation', *Literature and medicine*, 28.2: 185-99
- Freud, Sigmund 1917 'Mourning and melancholia', *The standard edition of the complete psychological works of Sigmund Freud* Vol XIV (1914-1916): 237-58
- Hooyman, Nancy and Betty Kramer 2006 *Living through loss: interventions across the life span* New York: Columbia University Press
- Hustvedt, Siri 2012 *Living, thinking, looking*, London: Hodder and Stoughton
- Kristeva, Julia 1989 *Black sun: depression and melancholia* (trans Leon Samuel Roudiez), New York: Columbia University Press
- Miller, Sue 2003 *The story of my father*, London: Bloomsbury Press
- Moon, Michael 1995 'Memorial rags' in GE Haggerty and B Zimmerman (eds), *Professions of desire: lesbian and gay studies in literature*, New York: MLA, 233-40
- Neil, Linda 2009 *Learning how to breathe: a true story of love, family and music*, St Lucia: University of Queensland Press
- Neimeyer, Robert (ed) 2001 *Meaning reconstruction and the experience of loss*, Washington DC: American Psychological Association

Novak, Philip 1999 "Circles and circles of sorrow:" in the wake of Morrison's *Sula*, *PMLA* 114: 184-93

Ramazani, Jahan 1994 *Poetry of mourning: the modern elegy from Hardy to Heaney*, Chicago: University of Chicago Press

Santner, Eric 1990 *Stranded objects: mourning, memory and film in postwar Germany*, Ithaca: Cornell University Press

---

#### ABOUT THE AUTHOR

Dr Rachel Robertson is a Lecturer in Professional Writing and Publishing at Curtin University, Western Australia. Her research interests include life writing, creative nonfiction, disability studies and motherhood, and she is Associate Editor of *Life Writing* journal. Her book, *Reaching one thousand: a story of love, motherhood and autism*, was published by Black Inc in 2012. Her work has appeared in anthologies and journals such as *Griffith Review*, *Island*, *Westerly* and *Best Australian essays*. She was joint winner of the 2008 *Australian Book Review*/Calibre Prize for an Outstanding Essay. Website: [www.rachelrobertson.net.au](http://www.rachelrobertson.net.au) (<http://www.rachelrobertson.net.au/>)