

# The Sister Box

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**Abstract:** This narrative explores the intersection of my work as a professional social worker in an oncology and palliative care setting and my previous experience of the loss of my sister. Despite being committed to reflective practice, I found that I was blindsided in the course of my work when my professional and personal worlds collided. In this paper, I detail my retrospective reflection on the emotional labour associated with working in oncology and palliative care, and how I had not recognised how the thread of loss running through my life was interwoven with my professional life. The discussion draws on narrative theory and meaning making as a way of making sense of the experience of when the professional and personal worlds overlap and asks if we, as professionals, can be truly authentic with our clients if we have not engaged fully with the self-reflective process.

**Keywords:** self-reflection, personal journey, grief and loss, meaning making, intersection of personal and professional

## Introduction

Despite having worked in social work for over a decade and then moving into academia and writing a PhD which focused on the importance of meaning making for important and/or traumatic life events, I was taken aback by my own reactions when encountering life-changing illness and death. Although my PhD focused on the importance of meaning making, and I have always had a strong belief in the need to make sense of the world around us, I had not recognised that need in myself. As professionals, it is easy to talk about self-care and the need for self-reflection, but what I recognise in myself is that my self-reflection related to traumatic life events and loss only went as far as I was comfortable. Deep-seated memories of loss were acknowledged on a surface level; however, their deeper impact within a work setting and at a personal level were largely ignored. As professionals, we can often function and operate very well on this surface level, but I wonder about the disservice we are doing to clients and indeed ourselves. For me, there was an element of being blindsided by the impact of loss in my early life when confronted by death and dying in my professional life. Cognitively I was aware of the connections between my early experience of death and my work in oncology and palliative care, but at an emotional level I was surprised at my limitations. It was as though I had opened the door a little to peek inside but remained outside the door at all times. If I went through the door and fully into the room, I knew that there would be pain and a reliving of early loss.

The initial part of this article focuses on an interaction I had while working as a medical social worker in an oncology unit in a large teaching hospital. This encounter, which lasted no more than ten minutes, had a profound impact on me and led, albeit slowly, to an examination of the impact of previous life events and my relationship with death. This process of self-reflection is underpinned by a social constructivist perspective. Neimeyer (1995) explains it well, commenting that constructivists construe the self more as a process than a product, and that there can be many possible selves. Self-development is an ongoing dynamic process in response to the

discrepancies within the self-system. In doing this retrospective reflective, I know that I would describe myself very differently now than I did ten years ago. Yes, there have been many changes in my life; however, I am thinking specifically about myself and loss. I also believe that, should I sit down in another ten years' time, there will be another version of me. The essence is the same and, for want of a better phrase, the ingredients are all there from before, just more ingredients get added in every year. The second half of this article engages in sense making of my experiences and discusses the concept of *bounded caring*. Oncological work exists at the intersection between emotional labour and professionalism. For many, professionalism is associated with an absence of emotional expression in the work environment, and yet oncological work demands emotional involvement to co-exist alongside professional behaviour. Wong et al. (2020) use the term “bounded caring” (p. 352) to describe the intermingling of these co-existing realities. The discussion is underpinned with the belief that it is essential to recognise that the development of identity is a temporal process and is grounded in narrative theory and meaning making.

### **Blindsided**

It began on a corridor, one humid afternoon in the middle of summer. I was not looking forward to going up onto the oncology ward because of the building work that had been going on in the hospital for several weeks at this stage. All the windows had been sealed shut to stop dust getting into the wards. The air in the ward was stagnant, and both staff and patients struggled to cope with the heat and oppressiveness. At least I knew I could escape to the relative freshness of my office, or take a walk at lunchtime around the grounds, so I felt guilty about my reluctance to go to the ward to walk, step by step, up into the stagnant air.

As I entered the ward, I saw her coming down the corridor towards me. I had met her almost six months previously, not long after she had been diagnosed with cancer, but had not seen her since. Again, the guilt surfaced—how had she been, I should have checked in with her. The other part of my brain was justifying my lack of contact with her, noting that she had early-stage breast cancer with a very good prognosis. She also had good support and assured me she would contact me if she needed to. As the only social worker covering all the oncology cases in the hospital and overseeing palliative care, it was not possible to do everything. Yet, I knew it was not good enough. I felt that I had failed her. I did not provide her with the support that she deserved.

It turned out that she had just completed her final treatment. She did not look excited or happy as I expected, but anxious and unhappy instead. I wondered why that was and found myself congratulating her on finishing and telling her that I was sure she was delighted, even though it was obvious from looking at her that she wasn't. She told me that everyone expected her to be happy and relieved, but she was not feeling happy. She was feeling anxious and confused and unhappy. She also said that because her friends and family expected her to be happy, she felt guilty for feeling unhappy. I realised that I had added to this pressure by placing the same expectations on her. I had never thought through what it must really be like to finish treatment, which was ridiculous considering the job I was doing.

I found myself thinking about her a lot over the following few weeks, and I began to realise the

assumptions that I was making daily in my work. I had seen her as “one of the lucky ones”—the cancer had been caught early and she had a really good chance of being cured. When it came to prioritising an ever-expanding workload, patients like her came somewhere near the bottom of the list. I knew that it was a fact of life that I had to prioritise, but I recognised that I had become complacent. Identifying these women with early-stage breast cancer as “the lucky ones” was not helpful or fair to them. The metaphor that came to mind was that we put these women on the conveyor belt of treatment, and for the majority, the conveyor belt moved smoothly towards the end of treatment. At the end of treatment, the women fell off the conveyor belt but no one, including me, checked to see where and how they had landed. This made me think further. Why did I not think it was necessary to check where they had landed? I realised that I had an expectation that they would pick up from where they had left off at diagnosis. As I looked at her face, I was looking at someone who was lost and afraid. She needed support—my support—and I had failed to notice that. She was so polite and gentle in her conversation with me when she had a right to be angry and demand my help. I was viewing the cancer as a hiatus in their lives, rather than a life-changing experience. Having reflected on it, I realised that that was how many of us working with these women viewed the experience. In a world where life was measured in survival percentages and stage of disease, we did prioritise cases based on that. At ward rounds there was a tendency to skip over people with excellent survival chances and focus on those with worse prognoses. There was no malice intended, and the sad reality of ever-increasing caseloads meant that choices had to be made; not everyone could be seen or attended to in the way they should have been. One colleague told the women that the cancer experience would be “a year out of their life” and to view it as such. Although it was said in an attempt to be helpful and comforting, I realised that it was neither helpful nor comforting for the majority of women in the long-term. More importantly than that, it was not true. How could being diagnosed with a life-threatening illness and facing your mortality be confined to just one year? I felt that I had unintentionally bought into the “medicalisation of emotion” (Manchester, 2015, p. 150). By this I mean that although emotions were acknowledged as a normal and expected part of life in the oncology and palliative care unit, a time limit was put on it. There was an implicit expectation of what a “normal” reaction was and how long it should last. With my social work background, I was disappointed that I bought into this measurement of what emotion should look like and how long it should last for.

I was shocked by the number of assumptions and preconceptions I had about working with women with early-stage cancer. I realised I was much more open to what a life-changing experience it was for people with other cancers, and I was confused why I felt like this. I think it was the fact that the women with early-stage breast cancer were curable and the survival rates were so good. In my mind I saw it as “the least bad option” and so didn’t focus in depth on what a traumatic experience it was for each woman. I was really forced to explore what it might be like when I went to meet another woman for the first time who had been diagnosed with cancer. She and I were born on the same day, possibly in the same hospital in Dublin. We both had similar backgrounds and lives, and the thing that resonated most strongly with me was that we both had young children of similar ages. Immediately I could put myself in her shoes. It is not that I didn’t feel empathy towards the other women, but in this situation, I reflected on two baby girls born on the same day, and how similar our lives were in so many ways except for cancer. It could have been me instead of her.

As she spoke about her fears and worries, her children, and the possibility that she might not see them grow up, I felt I got it. I thought of my own children, and what if I was the one, and not her, who was facing this possibility. I felt angry with myself for not truly understanding before that no cancer diagnosis can be considered lucky. Meeting her had an enormous impact on me that I only recognised later upon reflection. I began to worry about my own health, and whether I might have or get breast cancer. I would wake up in the night terrified about dying, trying to comprehend how I could stop existing, and trying to comprehend the nothingness of death.

I had met death before. My own sister died suddenly and very unexpectedly, and I was the one who found her. She appeared to be asleep, and yet the minute I opened her bedroom door I felt a stillness in the room. Even as a young girl I knew immediately she was dead, but I still tried to wake her. She looked the same as ever, her hair freshly washed and smelling of the shampoo she had used the night before. She was warm and peaceful, lying stretched out in her usual sleeping position. It was unbelievable that she was gone. That was the phrase that kept going through my head—she is gone. I wanted to follow her, catch her hand, and pull her back. How could she go? I was her person, I was her minder, and I had failed her. I was angry with her for going somewhere without me. “You know better than that!” my voice was shouting in my head. She was two and a half years older than me but had a mild intellectual disability, so I was the sister in charge. We were a team, she and I, and now she had gone off on her own without me. Who was going to mind her now? Who will protect her? How dare she go without me? How do I fill that piece of me that is missing?

Immediately following her death, a close relative wondered aloud if it was the best thing that she had died. I thought at the time that I could not have felt any more pain than what I was feeling at that moment, and yet I could. How could her worth as a person be so devalued because of her intellectual disability? I had no voice as a young girl to shout at this relative, “Your daughter is the same age! How can you say that? Is my sister’s life that valueless? How would you feel if it were your daughter?” I know this relative is not a bad person and, with extensive time having passed, I like to think that perhaps she was trying to process the shock and her words were badly chosen. In my more charitable moments, I believe that my relative was imagining the disappointments my sister might face in the future and was expressing, very badly, that she was glad my sister would be spared the pain. Once the funeral was over, there was very little talk of my sister. I returned to school distressed and traumatised by the suddenness of her death and felt very alone in trying to process her death. Each immediate family member dealt with their own pain individually, and there was a sense of “you just have to get on with it,” and that was what I did. To outsiders, I think I looked the same as ever, and the fact that I could hold it together in public was far more comfortable for them and me than outward distress would have been. There was evidence of distress though, but it was largely ignored by teachers and family. I failed a school exam for the first time in my life and went from being a highly academic student to a mediocre student. I remember being in an oral language exam and being asked to describe my family. I got stuck, not because I did not know the words in the other language, but because I did not know how to describe my family now. I managed to function and get through school, and I think that is what mattered to everyone around me at the time.

So, I thought I knew what death looked like, and I thought I didn’t fear it. But I did, and my greatest fear was leaving my children without their person, their minder. My fear of flying rose

dramatically at this time, and it was not really of crashing, but rather of crashing and leaving the children. Leaving them wondering where I had gone to, and their realisation that they would not be able to find me. This I realised is my greatest fear. I wondered how much my own history affected this, and how much every other parent feels like this.

### **Walking Fully into the Room**

I have read back about that encounter on the ward many times and how it led me to consider and really look at my thoughts and experiences about death. Every time I read the section about my sister and I ask, “Who is going to mind her now?” I cry. There is guilt still about not protecting my vulnerable sister, though the rational part of my brain knows that there was nothing I could have done. To deal with the trauma of losing her, I put her in the *sister box* and stored her in that box, on a high shelf, in a dark corner of my brain. I would take the box down every so often and take her out to remember what we had. Particular events triggered huge grief, such as the birth of my first child who is named after her. How they would have loved each other and how my sister would have cherished that relationship. For the most part, however, she remained in the box on the high shelf, not forgotten but put away. My guilt was triggered again when I met the patient on the ward. I had let her down during a very difficult time in her life. I had not been as available to her as I should have been. As with my sister and rationalising that I was a child and could not have changed anything, I could rationalise my guilt around the patient with the recognition that it is not possible for one person to see every oncology and palliative care patient and provide a comprehensive service. I saw the vulnerability in that woman’s eyes, the fear of where she was going next and what would happen next. I felt my protective instincts kick in and the need to reassure her that all would be OK. I had failed to protect my sister but perhaps I could protect her.

There is a new guilt. I see the pattern of fearing death manifesting itself in one of my children. My child comes downstairs well after bedtime, inconsolable about the thought of Mum and Dad dying, or the thought of “spending all of eternity on their own.” While knowing that some of this is a very normal stage of development, I am also aware this has gone on too long and that the worries are too intrusive for this child. I worry that my lack of reflection and meaning making somehow resulted in my fears being passed on to my child. There are so many layers to it; it is so complicated. This same child had an anaphylactic reaction to an unknown allergen at the age of three. I held my three-year-old child in my arms as he struggled to breathe and thought he would die. I remember the words in my head being, “Oh my God, not again. I can’t lose him too.” As he struggled to breathe, there was nothing I could do to help him. I could not change the course of what was happening. When I am up at night with him, trying to console him about his fear of death, I do wonder whether I have passed on my fear to him or whether he has a subconscious memory of how close he came to death and this is manifesting itself in the terror he is experiencing years later.

One of the most important things in trying to make sense of my feelings and why that encounter that day was a significant turning point for me has been to recognise that encounter not as the beginning, but as one of a series of events in my life. We cannot stop the personal and professional from colliding, as I realised when I met the client with whom I shared a birthday. The personal and professional can never be fully separated. The concept of time is central when

thinking about meaning making. To make sense of an event, humans need to understand, or try to make sense of, the sequence of events. Crossley (2000) elaborates on this: in order to portray human selves and behaviour in a valid way, there has to be an understanding of the inextricable link between time and identity. It is the connections or relationships between events that constitute their meaning.

The construction of self is a temporal process through which we have dialogue with different images of the self taken from the past and the future and mediated by the anticipated responses of significant and generalised others. (Crossley, 2000, p. 13)

From my own standpoint it seems as though the various images of self did exist; however, they did not talk to each other. So, the bereaved sister definitely existed, the mother with an ill child existed, and the social work professional working in oncology and palliative care helping others to manage their grief and loss was also present, but the dialogue between these selves did not occur. This led to a disconnect which only began to come to the fore because of that chance encounter on the ward. Time and narrative are very strongly interlinked, with time being essential when organising the narrative experience. Martino and Freda (2016) contend that the narrative of traumatic experience assumes the function of reconstructing the story of the continuity of life, including the personal story context, consolidating the interruption in time, and creating a new connection between the continuity and the discontinuity of the experience. This results in there being a meaning that spans the past, present, and future. In my own case, time has allowed me to reflect and unite the different strands that have run through my life in terms of loss or threat of loss. The experience of losing my sister at a very young age has certainly made me very aware of the possibility of losing my own child, but recognition of how those two strands are linked has meant that I can contextualise my fears.

The concept of meaning making as a form of storying resonates strongly. Arciero and Guidano (2000) describe meaning making as being an ongoing form of storying. It is a way of composing and recomposing one's life through shareable meanings that then accumulate and become life stories or narratives. To have a fully developed sense of identity and sense of self, the stories need to have a dialogue between them. If there is no dialogue or a deficit in the amount of dialogue, then the self is not whole. Neimeyer (2000) discusses the human instinct to *story* or narrate the experiences of our everyday lives and believes that this human orientation towards telling our story can be viewed as having three dimensions: personal, interpersonal, and social or cultural. In terms of the personal dimension, people categorise their lives into specific episodes and organise them so that they can be understood in the context of other experiences. It is in the development of the self-narrative where this personal dimension is most obvious, with Neimeyer (2004) defining it as

an overarching cognitive-affective-behavioural structure that organises the “micro-narratives” of everyday life into a “macro-narrative” that consolidates our self-understanding, establishes our characteristic range of emotions and goals, and guides our performance on the stage of the social world. (pp. 53-54)

I was unwilling to go on the journey to try to examine the strong, almost visceral reactions that I experienced, particularly when interviewing young women of my own age who had been

diagnosed with early-stage breast cancer for my PhD. It was easy to look at the surface and explain my own distress as being an expected result from witnessing the fears of these young women. To an extent this was true, and it would be concerning if one was not moved by the content of the interviews; however, I knew that it was deeper than just joining these women at an empathic level. White's (2007) work using the metaphors of journey and map in narrative therapy was useful to me as I tried to process my thoughts and feelings. His description of how people feel when first engaging in therapeutic conversations—described as a sense of departing from the familiar and embarking on journeys to new destinations without maps—really resonated with me. I drew comfort from his belief that as the reconstruction gathers pace it quickly becomes clear to clients that they are drawing from a stock of maps relevant to journeys already taken, and that they know a lot about mapmaking (White, 2007). When I finally allowed myself to stop and examine what was happening for me, I did feel map-less. I was not sure where this reflection would take me and worried what would happen if I took all of my stories out to look at them. Would I be able to put them back in again, and how would I be changed by doing this? When I did take the stories out, I could see the thread of loss that ran through. The visceral reactions were linked to fear of going through loss again and re-experiencing the loss associated with the death of my sister. I had a stock of maps related to the loss, and this stock provided not only a map of where I had been, but when put together, they provided my current location. The relief I felt related to the fact that my maps showed me a thread of loss—and fear of loss—that linked the experiences together.

The process of self-reflection has, I believe, made me a stronger practitioner, and I am sorry that it took so long to do. If I could go back in time, I would have urged myself to open the door and unpack the sister box much sooner. I would like to have talked about her more, but not just about her—about the pain that her death left us with. I remember the pain in my other sibling's face, and I wish that we had talked more. Like me, my sibling returned to education immediately after her death and progressed to graduation and beyond. We talked recently, as it would have been my sister's 50th birthday, and we really reminisced. We both reflected on how 31 years had passed and that she will always be 18 to us. For a moment it was like the three of us were there again as we spoke of her various exploits. Myself and my other sibling were far better behaved than my sister, or perhaps I mean boring. She lived her life to the fullest, doing things that I would never have dared to do, such as mitching (skipping) school, smoking, or stealing money from my mother's purse. I remember the kind of swagger she had as she returned from adventures with friends. I was always a little in awe of her daring nature, and it turned out that my sibling experienced the same feelings. It feels so wrong that she is in the sister box, when in her life nothing could have contained her.

There is a sense of guilt that I was not being truly authentic with the people that I worked with. I was asking them, particularly as participants in my PhD research, to open themselves up and talk to me about painful aspects of their lives, but I was not prepared to do that myself. As practitioners, we need to be aware of what we are asking clients to do and consider if it's something we have been prepared to do in our own lives. At the risk of sounding like I am excusing myself, I thought I was reflective at the time. I was not willfully setting out to be inauthentic. I thought I was being true at the time but, looking back to that time ten years ago, I can see now how compartmentalised I was. As Neimeyer (1995) says, self-reflection is an ongoing dynamic process and so this process of reflection is never done. There is never a point

at which we can truthfully say this is who I am and stay like that forever more. We are an evolving process, and our identities and self are changing and being modified.

As professionals, if we wish to be authentic not just to ourselves but also with the people we work with, we need to actively engage in this process of self-reflection and be receptive to the changes we encounter. The concept of emotional labour is a useful one, referring to the management of emotions during interactions to achieve a professional goal or maintain professional standards. When looking at grief and role identities, Theodosius (2012) notes that individuals become more aware of their emotions when they interpret them in relation to their identity. Emotions are central to the development of reflexivity and, given that emotions are a part of professionals' inner lives, these emotions are central for developing the skills of self-reflection and reflexivity (Archer, 2000). Burkitt (2012) uses the term "emotional reflexivity" noting that emotions are central in this reflexivity in the way that it "colours reflexivity and infuses our perception of others, the world around us and our own selves" (p. 458). In reflecting on the idea of emotional labour and emotional reflexivity, Wong et al. (2020) use the term "bounded caring" (p. 352), which I found particularly helpful. They discuss the idea that emotions are not clinical products that need to be managed or controlled but rather "experiences that connote human connections and understanding" (p. 360). Bounded caring refers to the situation where professionalism and emotional work intersect and can do so legitimately. Emotional work can enhance our patient encounters and our professional work, but to be truly effective it requires deep self-reflection. Wong et al. (2020) support this, noting that a key outcome of their study was the importance of professionalism and bounded caring as a site of expertise.

I had another encounter on a corridor a number of months ago, during the time I was reviewing and working on this article. The person was in distress because of some of the material that had arisen in the class earlier and had left the room to try to manage their emotions. As I approached the student, I thought about bounded caring and the intersection of professionalism and emotional labour. I sat with the student, and we talked and we shared. I have always shied away from sharing my past, but now I can see that there are times when limited, controlled sharing is appropriate. The student and I discussed loss and grief, and I told them that I had lost a sibling too. The look of recognition that passed across the student's face was incredible. It said, "You know this pain too." I will share more of my sister going forward and let that exuberant personality out of the box a bit more. I know that my experience of grief and loss is particular to me, but I recognise there are parts of that experience that might help someone else on their own journey of loss. This encounter has made me think further about how much we should reveal of ourselves and yet still work within the parameters of bounded caring, synthesising both professionalism and emotional labour.

### **Conclusions**

I have been trying to write this article for the past decade or so and, when looking back on the experience, I cannot believe how unaware I was of the impact of loss in my personal life and the impact of my work in the oncology and palliative care setting. To be more truthful, I think I was aware but did not have the courage to stop, and think, and look at the patterns. The loss of my sister was too big, and I was afraid that if I opened the sister box it would overwhelm me. Guilt



is the recurring emotion running through these reflections; guilt that I did not protect my sister, guilt that I didn't look after that patient as well as she deserved, guilt that my child is experiencing anguish about death. After my sister died, there was the expectation that we, the remaining family, should just get on with it. Although it was not spoken out loud, it was the clear message, as we each struggled with our emotions individually. I did get on with it and ultimately chose to work in oncology and palliative care. Looking back, I wish that someone had sat the young girl down who had just lost her sister and explored what the experience was like for her. Of particular importance would have been to examine the role of guilt at an emotional level. At a rational level it was very clear that the death was not preventable but at an emotional level there was a huge burden of guilt. I studied grief and loss as part of my training and continuing professional education and yet did not fully acknowledge the impact of my unresolved grief. In fact, I think had I been asked, I would not have identified it as unresolved. I acknowledged what I had been through and reflected on it, but not in the depth that I have achieved now.

So, all I can think, all I can hope as I write this piece is that it might help someone else open their sister box and look at what that loss means for them. As Perlman (1989) says, "We look back to see ahead" (pp. 1-2). Unless we draw all of the strands together and ensure that the stories we tell have a dialogue between them, we are only creating a partial identity. The stories, good and bad, need to be joined together with the thread of our life to really tell who we are. As professionals, we need to be mindful of and reflect on the intersection of the personal and professional. Not only do we have a stock of maps relevant to other journeys taken, we also have a stock of tools to help us reflect and become better professionals. The onus is on us to open the door and walk fully into the room.

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