

Counselling conversations with parents whose child has died during or soon after pregnancy<sup>1</sup>

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### Abstract

When a baby dies, before or after his or her birth, we (counsellors and lay people alike) are often at a loss as to how to help. This article addresses the delicate conversations needed to demonstrate how relational narratives can live on after the death of a baby whether he or she dies in utero, miscarried or born still. Using re-membering practices and narrative counselling, we explore how a deceased child's ongoing identity can continue to inform sustaining narratives for those living with grief.

Key words: grief; bereavement; narrative counselling; re-membering practices; infants; death of a child; loss

## Introduction

In 2006, I (HGK) became pregnant with twins after years of fertility treatment. Like many parents, I was worried for the usual 21 week scan, but not all was routine. The scan showed serious defects in one of my twins. In a split second, my life changed dramatically from the joy and happiness I felt when I learnt I was expecting a boy and a girl, to the devastation of being told my little girl had serious difficulties that would dramatically affect her life. She would not be able to live the life I had imagined for her, and the conditions were likely to end her life before she was born. Little did I know, my little girl would change my life even though she never lived physically beyond 32 weeks' gestation.

This little girl, Augusta, taught me how, even before birth, children affect their parents, inviting strong emotional bonds and learning about what it means to be a parent. When a child is born dead, many overlook this existing relationship and the knowledge it generates. In many ways, Augusta contributed to a much richer understanding of parenthood than discourses that reserve the status of 'parent' for those with full-term, living children.

Since Augusta died, she has influenced my professional life. In my work as a psychologist, Augusta's life, and death, led me to work with parents who have experienced the loss of a child during pregnancy. I have been introduced to many children who have died during pregnancy and who have, in similar ways, contributed to richer understandings of parenthood for their family both during the time they were alive and after their deaths.

My experience with Augusta and these other children led me to Lorraine Hedtke and her influential work on re-membering lives through 'conversations with the dying and the bereaved' (Hedtke & Winslade, 2004). We began to collaborate in exploring how general ideas about re-membering could be used specifically to enrich conversations with parents of a child who died during pregnancy or soon after birth. It was conversations with those parents who consulted us giving value to the life of the child they had lost and who were experiencing the despair of a lost relationship with this child. These were parents who even spoke about their child, no matter the age of the foetus, as a child or a baby that had died, but may have not yet found a vocabulary to speak about the relationship or been supported to develop this. In this article we will use the words 'child' and 'baby' as to echo the words that parents are using that carries the meaning of what they experienced they have lost and continue to relate to. We recognise there are many differing circumstances that may lead to a baby's death during pregnancy, or just after birth.

We also recognise there are many different issues around parents and gender non-conformity, and we will be referring at times to parents using some gendered terms like 'mother' or 'father' without specifying gender fluidity. We will not in this article address these varying circumstances, but wish to be acknowledging of these contexts. We will address the thinking that informs our questions. This remains constant regardless of these differences in circumstance. Specifically, we are interested in how can an ongoing, acknowledged bond with a deceased child help people to respond to the devastation of such a death, and become the foundation for unforeseen meanings and actions.

This article is the result of the collaboration between the authors. It contains transcripts from parents who have had a child die before birth, all of whom wanted their stories told, and, in fact, saw their participation in this paper as an opportunity to ensure their child's life would continue to matter.

However, before we speak about the beauty of an ongoing relationship with a deceased child, we need to establish some important distinctions between conventional grief psychology and narrative approaches to grief.

## Paradigm distinctions

Narrative conversations about a child who has died before, during or soon after birth are informed by a different set of assumptions about responding to pain and despair. Unlike conventional grief psychology, which often assumes the end of a relationship, a narrative approach to death and grief acknowledges that relationships between the living and the dead can continue to be viable, accessible and potentially transformative (Hedtke & Winslade, 2017). In other words, a baby who has died does not cease to have influence on his or her parents, nor does this child stop mattering simply because he or she is dead. When grief psychology models of the past hundred years insist on 'letting go', 'moving on' and 'acknowledging the loss', there are limited options for parents to form an ongoing bond as a response to grief. We would suggest that this severing of ties leaves the relationship with the deceased child unacknowledged, and exacerbates pain, yearning and despair. In recent years, there has been a small shift towards holding onto memories of the lived relationship (for example Worden, 2009): however, this change has left little room to publicly construct the many ways in which a deceased child may have ongoing influence and continue to be an integral part of his or her family.

To remember a deceased child, or to cultivate a continuing of the bond between the living and the dead, does not

mean that despair is magically erased. But death does not cancel love; living people continue to love and relate to the dead person in their mind, in their thoughts, in their feelings and in their actions. The relationship does not come to an end (Hedtke & Winslade, 2017). A narrative counselling practice can encourage people to find both internal and external resources to respond to the hardest moments in life by exploring a storied connection between the living and the dead, and ways to make meaning out of the pain that death and grief can bring. This might even include imagining the 'voice' or the hopes of the deceased child in questions exploring a future in which the child's influence and 'presence' are part of a continuing relationship (White, 1989). For those parents who feel uncomfortable speaking the imaginal voice and the imaginal hopes of a deceased child, other pathways and questions can create a storied connection between the living and dead.

Our experience is that this practice of questioning develops new pathways where loss and even deep yearning can be held alongside the recognition of a continued bond with the deceased child.

The notion that death does not cancel out the importance of a person's life was featured in writing and research by anthropologist Barbara Myerhoff (1978, 1982), who coined the term 're-membering'. According to Myerhoff (1982), remembering is a 'special type of recollection' that establishes the 'members' of a person's life. It is an active process of conjuring these members, so that 'life is given a shape that extends back in the past and forward into the future' (1982, p. 111). Michael White (1997, 2007) built on Myerhoff's concept of re-membering to support a sense of belonging anchored in preferred stories that include the living and the dead. White's seminal article, 'Saying hullo again' (1989) introduced an innovative counselling approach that challenged metaphors about saying goodbye to a deceased loved one. He drew on Myerhoff's work to use stories and meanings as tools to bridge the living and the dead. Remembering brings to life the stories, dreams and hopes of those who have died (Hedtke & Winslade, 2017). These practices, although still marginalised by the dominant ideas in Western medical discourses, have had some successes in challenging the advocacy of severing of ties with the deceased. The ideas and practices have influenced a variety of therapeutic arenas, but have not yet been fully developed. We hope to extend the use of re-membering conversations to explore the ongoing connections between deceased children and living parents.

It is possible to re-member those who have died having never spoken or worked or shared aspirations and desires. Re-membering allows for the living to conjure an imagined 'voice' and dreams which becomes the very real influence of those who have died. It provides a structure for ethical living by folding meanings from the ongoing relationship with the deceased child into newly acquired skills, meanings and values. For example, a mother whose twin sons Ludvig and Siggurd died at 23 weeks gestation explained:

When I think about Ludvig and Siggurd I think they make me a better person. They remind me of 'what is important in life'. They often have me act on this by stopping my friends when they get too caught up in daily problems and they forget what is of such a great value just in front of their eyes. Before Ludvig and Siggurd I did not really pay attention to this.

## Membership

Myerhoff recognised stories as living on after death because stories flow between people and no one person is the sole author of their story. This idea flies in the face of intellectual property rights by suggesting a communality of authorship, but it does directly bear upon the conversations we are having with parents whose child has died before or soon after birth. Membership of a person's life, according to Myerhoff, belongs to the group of people who hold particular stories, and the rights and responsibilities of tending to them. Thus, Myerhoff explained:

A life, then, is not envisioned as belonging to the individual who has lived it, but it is regarded as belonging to the world, to progeny who are heirs to the embodied traditions, or to God. (Myerhoff, 1982, p. 111)

The ongoing stories of a deceased child do not remain with that child, but belong to the people who have held love and hopes for this child, members of the child's life. Not unlike when a person dies who has lived for one hundred years, those who love and care for the deceased continue to carry the membership, honouring the stories and love, and continued points of connection with the deceased. Membership creates a placeholder where the deceased child can always be found. Membership does not relegate the deceased child to the past, but opens opportunities for parents, families and communities to recognise the child as an ongoing part of their lives. Membership makes visible people's links with the child. One mother, whose son died at 24 weeks, explained:

I have had a couple of events recently where I am meeting people and they say, 'You have the two

boys'. That's hard, because I want to say, 'I have three boys and I would love to tell you about my other son'. But if I tell them I have a third child but he died, then I get this total sympathy that doesn't feel right ... When I am with people who knew my son, I'm good. Everyone knows about him and everyone talks about him. The pain is really when I am in a situation where he is just not known. Or that even if he is known about, he is not acknowledged. That's really hard, because he is still here for me. I am not actually holding his hand, but he is still here. There's joy when others know too that we are holding his hand.

Membership can be reinvested and reinvigorated through re-membering conversations, which speak to how the relationship continues to matter or to give a sense of purpose. As Myerhoff (1982) explained:

Such re-membered lives are moral documents and their function is salvific, inevitably implying, 'All this has not been for nothing'. (Myerhoff, 1982, p. 111)

## Re-membering children who have died

Drawing on the ideas of Myerhoff and White, it is not difficult to envision a re-membering conversation about an adult who has died. It can be easy to conjure up life stories, memories, experiences and times shared with the deceased. The bereaved often have a host of such recollections to draw from in order to establish a new appreciation of their connection. This can be used to craft a future in which the stories of the deceased person continue to feature prominently.

Re-membering conversations about deceased babies, however, require a different line of enquiry. The span of the lived relationship between the parent and child may have been a short period prior to a miscarriage, pregnancy termination, or stillbirth. However, we can draw on the hopes, dreams and wishes parents had for the relationship. and tie this to the experiences of pregnancy (and birth, if experienced), and the possible future life of the connection. Through these conversations, a sense that the life of the child matters can become the focus, rather than the way in which the child died. This can serve as a foundation for continued connection between parent and child. There are, however, specific challenges in making the relationship visible for the parents and for audiences of concerned people, in order to identify places where the child's life matters and continues to be a part of other people's lives. As a mother whose daughter died at 42 weeks of gestation explained:

I think it was harder to lose Elisabeth at such a young age, because we don't have any experiences with her. If she was three years old then we would have had the memories to hold onto.

If membership creates a sense of belonging to 'a club of life' (White, 2006, 2007), then it can become a vehicle to transport us to where a deceased child continues to live. In this club of life, we can recognise that stories about a child exist long before the child is born. We can explore and craft a story through enquiring about moments of interaction with the yet unborn child, when the parents of the unborn child were relating to him or her, making the relationship ever increasingly visible. These moments can bring into focus the relationship between parents and their dead children. We can even look to times before a child is conceived, asking about their preparations for pregnancy and what these testify to.

A deceased child has a place in their parents' club before and after his or her life. The 'voice' of the deceased child belongs in this club too, and this guides the parents, as if in real time, in how they conduct certain aspects of their life and even how they address the pain of grief. A father, whose daughter died at 22 weeks of gestation, stated:

We often ask ourselves what would Maria say. She is wise, she gets to have the role of supporting us in doing what we feel is the right thing to do. She is our little helper. It is nice to know she can be part of our life.

Parents' hopes and wishes for a deceased child's continuing influences on their life can make the child an active lifetime member of his or her parents' club. Counsellors can look to the intentions that the parents hold, and how the parents can enable these influences. We can even look for ways the child has influenced them to stand in opposition to the discourse of moving on or forgetting that is found in conventional grief psychology (Worden, 2009). When we underscore the wishes and hopes the parents held (or hold) for their child, it is almost as if we are giving agency and voice to the deceased child. This line of enquiry creates a sense of agency which the parent carries on behalf of the child who has died. This can be seen in a conversation between a mother whose daughter Anna died at week 40 of the woman's pregnancy, and the author (HGK):

**Helene:** How did Anna come into your life? Did you fight for her or did she come easily?

**Karen:** I fought a lot. I went into fertility treatment. I tried for one year to get pregnant and I almost lost hope. And then suddenly I got pregnant.

**Helene:** Wow, so you fought a lot for her. What did Anna

do to you, when you discovered that you were pregnant with her? Did she create certain feelings

in you?

**Karen:** [Smiles] Yes, she made me so happy.

Helene: Wow, so she made you so happy. Was it a kind of

happiness you have experienced before or was

the happiness she created different?

Karen: It was very different. It was a strong feeling of

meaningfulness.

**Helene:** Can you tell me more about that meaningfulness

that Anna so strongly connected you to, that she

made you experience?

**Karen:** It was a meaning about how much sense it makes

for me to become a mother.

Helene: What did she make you experience about being a

mother in the moments with her in the pregnancy?

Karen: The experience of wanting to take care and

protect ...

Helene: How was that feeling? Did you like it?

**Karen:** Yeah, it was so nice. It makes so much sense.

It gives much more meaning to my life than

anything else.

Helene: Wow. Can I ask if you think that is a big or a little

thing to open a mum's eyes to?

Karen: It is huge thing.

**Helene:** How is that for you that Anna has done that?

**Karen:** It makes me proud.

The questions are specifically crafted to be respectful of the deceased child's ability to imprint on the connection between her mother and the child. This respect becomes possible in a suspended account of time as we consider questions about before the mother was pregnant, during the pregnancy and since the child has died. This threads a theme of connection that has duration through time (Bergson, 1911), providing entry points into a relationship that can continue to travel throughout the mother's life.

# Standing against the invisibilising of a deceased baby

For some parents, grief following the death of a baby can be compounded by discourses about when in the life trajectory a baby becomes a person worthy of being grieved for (Butler, 2004). It is these discourses that create comments like, 'good you didn't know them very long or your grief would be worse' as falling into ways of making narrow meanings. These convoluted conversations also work their way into discussions about pregnancy termination as well that imply limited opportunity for grief or to examine the impact of an ongoing relationship. We do not wish to step into this conversation in this article, but do notice that considerations about what constitutes a grievable life have differing historical and political discourses that swirl around them. These same discourses sway conversations and meanings when speaking of a child who has died in utero. miscarried, terminated, or one who has died after being born alive. The power of the discourses can silence parents from making a relational connection with their deceased children, for example through dismissive comments that speak about an 'it' rather than a real child. Many parents are familiar with comments such as, 'it is good that it died before you got to know it', 'it was just a little foetus, now you know you can get pregnant', or the child was 'needed in heaven'. The loss that a parent might feel can be swept away by treating the loss as less than that of a full-term pregnancy or a child of a few months or even years.

Re-membering conversations with parents challenge invisibilising discourses about pregnancy loss. If we ascribe to the unborn child the capacities of a little person who is in relationship with his or her parents, we are freed up to speak differently. We can call upon the deceased child to weigh in on conversations with his or her parents, and to ascribe meanings between the living parent and the deceased child. Further, we can enquire about the meanings that were made while the child was developing. This avenue of enquiry can elicit many unnoticed and untold stories of times when the parent(s) related to the yet unborn child. Stories start to develop about how the little child had already influenced them in significant ways, often calling them into new ways of being. These are stories that might otherwise go unnoticed. Jill, whose daughter died in Jill's twenty-second week of pregnancy, illustrated this point:

I hadn't thought about how much my little daughter made me into a mother. All these experiences with her during pregnancy. It is so nice to know she has made me see the value in 'mother-caring'. And to know that even though the grief has been hard on me, I want to experience being pregnant again.

Asking questions such as, 'What did your little daughter do to you when you first noticed you were pregnant with her?', 'In what ways did your daughter teach you about the feelings, thoughts and actions of being a mother while you were preparing to be pregnant or when you were pregnant with her?' These questions open possibilities for the development of new meanings, forming a relationship between a parent and her deceased child. They actualise what otherwise remains virtual (Deleuze & Guattari, 1994). Jill, for example, began to speak about how her daughter changed her into a mother and made her think very differently about herself and her life. This became an opening for her to consider a future path, in which she feels the urge to be a mother for another child. The opening can be directly linked to her deceased daughter and even affords some credit to this little child. Thus, we could ask, 'What difference does it make for your motherly heart to know your little daughter taught you the value of being a mother?', 'What might your daughter know about your love of being a mother, that she might wish you to make use of when you get pregnant with her little brother or sister?' This knowledge is ascribed to what the daughter made possible for her mother to experience. Without the daughter's influence, the woman may not have known (in this instance, the experience of being a mother, for example, was only known through this pregnancy and its subsequent loss). When we centre the deceased child in this way, the child is granted a renewed position in the parent's club of life. The deceased child continues to be influential; they are not just a foetus who came to nothing.

# Double listening

Using the concept of discourse (Foucault, 1989), Michael White introduced the therapeutic application of 'double listening' (2000). This practice is based on an understanding that a story implies its opposite: 'hot' can only be understood and defined in relation to 'cold'; 'dark' in relation to 'light' (Derrida, 1976). In counselling, double listening means we are alert to the story being told, and to what is missing from it; the problem story and the counter story. In grief counselling, this may mean that we hear both the pain of loss and the story of connection; where there is despair, there is also testimony to love. Double listening allows both stories to exist in a dynamic tension, rather than privileging one story over another. We can see this in the way the following mother speaks of her deceased daughter who died at 42 weeks of gestation:

When I am at the graveyard, I think about how Rose might be freezing. I know it is stupid, but I don't want her to be cold or alone.

The desire to care for and comfort her daughter is in direct conflict with the 'reality' espoused by conventional grief psychology, which might defer to a biological reality of life and death. In 1917, for example, Freud wrote about how it was normal for reality to 'gain the day' (Freud 1971/1957, p. 244). Rather than condemning her 'stupid' thought as unreal, double listening captures what appears contradictory. It allows the counsellor to hear the 'both/and' in order to make possible an exploration of the meaning in her statement: being a compassionate mother, one who continues to love and protect her daughter from the harsh parts of life. Even if the mother herself is swayed by the discourses of conventional grief psychology, a counsellor can gently explore the other side of the story too. Remembering conversations incorporate double listening to attend to non-dominant stories that affirm love and afford the deceased child a continued role in the family. If the task of caring in parenthood continues, then new ways to speak about a relationship with a deceased child become possible, as suggested by the following mother, whose daughter died when the woman was 38 weeks pregnant:

It is like when we talk about Molly in this way it becomes possible not only to talk about all the things we have lost and feel so sad about. Now we can connect her with something positive.

# Introducing others to the deceased child

There has been a great shift in some medical circles, which has led to opportunities for photos to be taken of a deceased child in hospital (Blood & Cacciatore, 2014). Post-mortem photography has offered parents a tangible entry point into a story that can be shared with others. And while not all people have photographs taken for a variety of reasons, there are many possible ways in which parents can introduce others to their child who has died. However, this ongoing introduction can be limited, if not crushed, by the ways information is received and the powerful effects of dominant discourses.

It is not unusual for parents to be told, directly and indirectly, not to talk about the loss of an infant. Bereaved parents and those around them are recruited into silence in the belief that talking about their dead child will remind them of their grief and sadness. This same discourse can create silence by suggesting that displays of emotion or tears will make others uncomfortable. A father whose seven-year-old son had died described it this way, 'When people don't talk about my son, it is like my son dies for a second time'. Even well-intended and inadvertent comments can render the dead child

invisible, as Jill, whose daughter died at 22 weeks gestation, commented: 'My mother-in-law said to me that it is like a tumour: you'd better forget about it and get over it'.

These silencing discourses strongly suggest that it is better not to talk about the deceased child. As a result, this mother, and many parents like her, found herself alone in remembering her daughter. Even though the comments might have been intended as supportive, they isolated Jill and limited the ways her daughter could have a future. They prevented her daughter being known by others and erased Jill's opportunities to allow her daughter's life to influence others.

In our counselling conversations, we endeavour to discover what kind of life, purpose and meaning the parent created in relationship to the deceased child. As this meaning is being shaped over time, the ways the dead are spoken of change. The dead can even significantly influence others who are introduced to them. For example, a mother whose daughter died at 40 weeks' gestation said,

After we have started to talk about Sophia and how we still relate to her, my parents-in-law have started to talk about the little girl they lost 30 years ago, and my father-in-law for the first time has been able to talk about the feelings he still has for his little girl.

When this mother's little girl was talked about, her stories actually had the ability to influence her grandparents in significant ways, making possible a renewed connection between her grandfather and a deceased great-aunt.

When parents are not able to talk about their child who has died, they feel that they are letting the child down. Parents become the conduit to keep the child's stories and presence alive. It is almost like the parents become the biographers who understand the importance of their child not being forgotten. They intimately know that the connection between them and their deceased child continues, even when they might be at a loss about how to put this into words. The parents can inform and educate other people about their insider knowledge of the ongoing relationship and their knowledge about their children's identity continues to matter.

We can also speculate with parents about what others can learn from them sharing their continuing relationship and experiences with their deceased child. How can their sharing transform the traditional understanding of grief as ending the relationship with the dead child to a new understanding of moving on in life with a living and continuing relationship to a deceased child. The shared experiences of these parents can change the language of outsider witnesses, who can

come to see them as not only showing grief symptoms but also continuing their parenthood. The following excerpt illustrates how parents' expertise can be cultivated and meaning formed around larger themes of a deceased child's life. This particular couple consulted with the author (HGK) after the death of their daughter at 24 weeks into the woman's pregnancy. They were sharing the effects of other people's silence about their daughter's life and death.

Helene: I am not sure that people know about your relationship with your Mary. I am thinking that people don't know what to ask about in regard to Mary, did you know about this yourself before you experienced these things with Mary?

Stefan: No, not at all.

Else: No, I didn't. I think I wouldn't have had an understanding of how it is to have an angel child.

**Helene:** So in a way, this is what Mary has brought into your life? She has changed what you know about this?

Stefan: Yes she has.

Helene: You said your parents' response to your tears when you talked about Mary was to change the subject.

What do they need to know about the tears for them to respond in a different way?

**Stefan:** I think they need to know that they don't have to fix the tears. I want the tears to be there, because they are connected to the feelings I have for Mary. I like to talk about how I relate to Mary.

**Helene:** And what do they need to know about this, so they don't worry about this as grief?

Else: I think we need to tell them that Mary is our angel child. We will always connect with her and we don't want to change that.

Parents are positioned to educate others about the ongoing connection between them and their daughter so they are no longer positioned as helpless people being victimised by the pains of grief or defined as failing the norms of proper grieving by letting go. They act and speak their wisdom of relational connection to a child that is no longer breathing. This particular conversation continued beyond the bereaved parents' hope their parents might respond differently:

**Else:** My father-in-law actually suggested that I should make contact with my work and educate them on

what to do when you experience grief. We have no policy on this. My boss didn't respond to what happened when Mary died. He was silent. I have thought about this, about the importance of talking about dead children. I want to develop a policy about how to respond.

Helene: If Mary knew she was influencing her mother to stand up for this and make this knowledge more visible, what would it do for her? What would it do to her understanding of herself knowing she is in this work of changing things for future bereaved people?

**Else:** [Smiles] She would be proud. I think she would like to change things for the better.

#### Conclusion

In this article, we hoped to shed light on the significant relationship that can develop between bereaved parents and children who die during pregnancy or soon after birth. It is possible to identify places where a child who dies during pregnancy, or at birth, significantly contributes to his or her parents' lives, for example by highlighting the strength of a family to stand together. We hope that you, the reader, will be excited by these ideas that can support and enrich responses to parents who experience the despair of their child's death. We hope that the article can lay ground work for a new kind of conversation in which the identity of the deceased child and their relationship with their parents is richly narrated; conversations that carefully explore and support parents' preferences about how their relationship with a deceased child can continue long after the child's death. This is predicated on a belief that a relationship with a child develops long before the child is born, and that for many, a storied relationship with an unborn child develops even before a child is conceived.

Double listening allows us to explore unnoticed and untold moments that have unknowingly constituted this relationship during pregnancy and after the child's death. Capturing these stories can contribute to the bereaved parent's identity, underscoring what they value in life as a way to create meaning. These stories can stand against dominant stories of loss, and can contribute to lessening the pain of grief and heartbreak. When parents are no longer restricted to talking about their child only in relation to his or her death, they can also speak to the ongoing gifts of their child's influence:

After our last conversation, I have started to think about how my little daughter has contributed to my

life. I have only worried about how I was contributing to her experiences of life. When I think about her contributions to 'how I do life differently', it makes me proud. It makes me feel that she is a part of me that I am carrying along with me in my actions.

Death does not remove a deceased child's place in their parents' life. Narrative practices affirm this all-important relationship, and invite stories of the deceased child as continuing to have agency in their parents' lives. With just a slight shift, parents can not only honour the memories of their deceased children, but can craft a continuing relationship with them by identifying places where their child's hopes, values and influences can continue to be lived:

Since our last conversation about Roy, I have made much more space in my heart to connect with Roy's voice. I have, for instance, thought about what Roy's voice would be in regard to mine and his father's relationship, what would warm his heart to see me do when I miss him. It has helped me reach out in those moments for his father and ask for a hug. When I think about and imagine Roy's voice and I act on it, it makes me feel a warm connection with him.

As therapists, we have come a long way since Freud declared that grief symptoms should be dealt with by letting go of the dead one (1917/1957). We have gradually shifted to seeing the value of keeping memories alive and acknowledging the continuation of a bond (Klass & Steffen, 2017). This shift is important beyond therapeutic practice. For far too long, grief has been widely seen as an individual problem to be dealt with in a prescribed way. We hope to broaden perspectives on grief and to look at how we as a society render bereaved parents isolated or pathologised in their efforts to remember their dead child. We would invite others to consider not only the ethical implications of honouring and incorporating a deceased child's memory and voice for parents, but, perhaps even more importantly, to consider the potential devastation when this does not happen.

#### Note

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