

# Peeking inside a conversation between two art therapists talking about clinical work in end-of-life care on a wintry afternoon

Jody Thomson and Judy King

## Introduction

Jody Thomson facilitates group art therapy with adult cancer outpatients at a large metropolitan Sydney hospital, and runs a weekly community art-based cancer support group in Western Sydney. Judy King is the art therapist at a children's hospice in Sydney, looking after children with life-limiting illnesses for respite, and end-of-life admissions. This paper begins in the middle of their conversation, as they talk about Judy's hospice work and look at some of the response images she makes in her journal on the ferry ride home from work.<sup>1</sup>

**Judy King:** ...that was about a little boy who died a few hours after he was born at the local hospital. His mum and his young brother Tom wanted to spend more time with this little boy, this little 31-week-old. We worked together, Tom holding his little dead brother in his arms... I sat with the family for around two hours, memory-making.

It started in the tea room as I dunked my tea bag at the sink, standing next to the grandmother. She just wanted to talk... and talk she did, about various family dynamics amongst her children. Finally, we both walked back to the room with our mugs of tea and I tentatively suggested perhaps doing some handprints for memory-making.

I gathered together all my materials and went into the chilled room... it's kept cold for the little one in the cot... and I remember walking in to see him... it was just myself at first, which was good. I think I just wanted a moment with him by myself... and he's got a little bonnet and he's all wrapped and looks cosy... I think I touched his cheek and then picked him up... it was the first time I'd picked up a dead 31-week-old baby. As a nurse, I've looked after plenty of adults who've died in intensive care, but not children.

Tom wanted to hold his little brother. We spent quite some time choosing and making colours. Tom was very particular – he didn't want red, but maroon for his hand, and together we mixed the colour, with him directing how much more blue to add to the red. Mum chose purple, and Tom chose green for his little brother Ben.

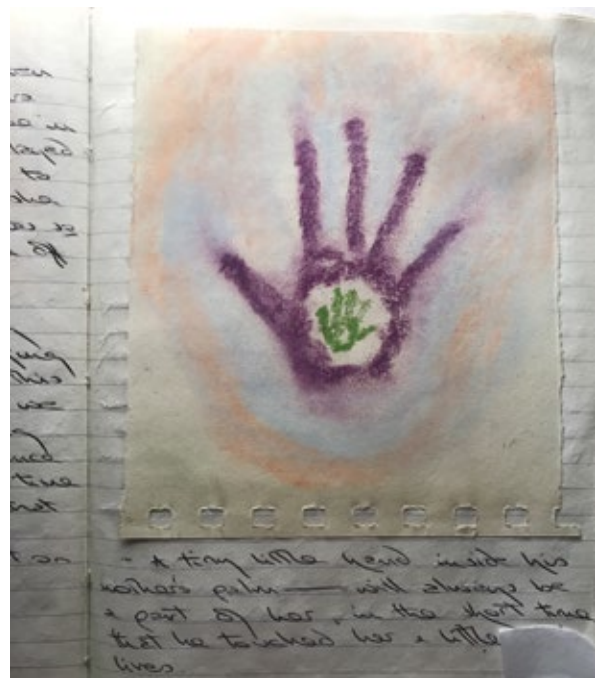


Figure 1. Judy King, *Art response to Ben's family*, pastel on paper, 310 × 200mm.

The text on this page reads: "Mum's sister came and wanted to hold little Ben, so I stayed with her while Mum and grandmother went to get some lunch. After a little while she got quite distressed as he was SO cold. I gently took him from her, placed him back in the cot and followed her into the corridor to check in. She leaned into my shoulder as she cried saying 'I don't know how you do this work'. I replied that we were glad that we are able to make a small difference to families at such a sad time – I really meant that."

Written under the image is: "A tiny little hand inside his mother's palm... will always be a part of her, in the short time that he touched her and little Tom's lives".

*Jody Thomson: That's so incredibly sad... what an amazing kid.*

**JK:** Amazing boy, and he was even joking at times – his capacity to hold his dead brother and be supportive to his mother really impressed me... I was really glad I could do it.

**JT:** *I can work with adults... but children... and the mum would have had to deliver the baby... I can't even imagine what a dead baby looks like.*

**JK:** Blue, and tiny, and frail...

**JT:** *I remember the first time I touched a dead body I was so shocked, really shocked at how cold and sort of plasticky-grey the skin felt. To suddenly realise that the cheek you are kissing goodbye feels so cold was really confronting... but a baby...*

**JK:** I remember wondering how stiff his little hands might be to unfurl so I could make a handprint, but it was fine. That's what happens with some of our other children, part of their condition may mean their hands are clenched, so sometimes after they've died we may make prints for the family then... if the family want it... it's a sad thing, but then the contractures have relaxed.

**JT:** *Did the mum know that there was a problem?*

**JK:** Yes, she knew that the child was very unwell. He'd lived for a few hours and they'd resuscitated him initially. The midwife at the hospital told the mum that if they wanted more time [with him], they could come to us. Dad never came, but they also have another young one, so he stayed at home.

**JT:** *So is this an important part of what you do – this memory-making?*

**JK:** Yes, it's a chance for them to make their mark somehow in the world.

**JT:** *And you? What was that like for you, being in that room? Did you go into nurse mode?*

**JK:** A little bit... there was a point when Tom got his little brother's thumb, and held it up like a little 'thumbs-up' and said, "Ben's giving us the thumbs-up", which was the most beautiful moment. And I thought, wow, I'm part of something really precious here. I couldn't tell you how long it was... I think I spent a few hours with the family. And I went to the funeral a few days later with the social worker, which was good, so I could reconnect with the family, and they spoke about how precious their time with us was.

Jody turns the pages of Judy's journal, and asks:

**JT:** *Was this one (Figure 2) about another baby?*

**JK:** No, this one's about a little boy called Dean... he was very ill and he knew that he was dying... the family was quite open to having those conversations... we were going to make a family tree with his little sister and his mum and dad.

He was watching tele with Dad on the bed and I said, "Do you mind if we just sit here on the end of your bed and do some art?"



Figure 2. Judy King, *Art response to Dean's family*, mixed-media, 310 × 297mm.

Judy has written beside this image:

"I found this nice piece of canvas paper and so enjoyed the watercolours blending on it... I already had the purple painted strips of watercolour paper that I tore... And I felt they became like trees in a forest... And then the central 'earthy piece' became like a knot in the wood of the trunk (which got blended later)... just like those I made in little Dean's tree with his little sister and extended family creating their family tree.

"As I looked on I saw a chasm... and how I'm bridging the chasm with my tree... within the family. How they didn't want the enthusiastic sister's footprints in the roots of the tree but rather those of the reluctant brother. I felt the tension for that little girl, left out on a limb a little, as all the attention is on her brother."

Dean's little sister and the resident dog Frankie were on the bed too – Frankie is quite intuitive, knowing when families are having a sad time.

So we started creating a tree... and Mum really wanted Dean to be a part of it. I kept saying, "It's okay not to, just to watch is ok too"... I gently suggested maybe just one little fingerprint... but he said "No"... and so he sat quietly, looking on. Right at the last moment, he put out his hand to me and held it there, looking at me intently, and I said "Do you want?"... and he said "Yep... yep"... so I quickly put the ink gently on his hand and we placed two handprints for the base of the family tree. Then I literally threw the canvas to one side and rushed to get the wipes to clean his hand, as I knew he didn't like paint on his hands. I was gently rubbing his hand and he's saying "Get it off, get it off" so I rubbed a little harder to remove the blue ink... deep down he knew his family really wanted it.

**JT:** *That's a lot of deaths we've been talking about – and you're still smiling at me...*

**JK:** I love this work, it's the best job I've had in 30 years, and probably the worst paid.

**JT:** *So why do you love it?*

**JK:** I love it because I'm part of a team. It ties [together] my nursing and art therapy hats... working with children... some people really get what I do and others don't, maybe some think I'm a diversional therapist... but a strict psychodynamic approach just doesn't work in this kind of place, making one-hour appointments just doesn't work – it's more organic than that... being flexible is really the key.

People think that it must be a sad place, but it's not, it's a very unusual place, it's actually a privilege to work there.

Jody turns another page of Judy's journal.

**JT:** *I find this image (Figure 3) really haunting...*

**JK:** Yeah, Matthew, he came for unaccompanied respite for five weeks while his parents went overseas for a holiday.

**JT:** *Part of me is going, 'what? they left him for five weeks?'*

**JK:** They're the most beautiful family and they haven't had a break for such a long time – families do need to have holidays, the two of them were just having some time out and that's okay. This teenage boy has a disease that meant



Figure 3. Judy King, *Art response to Matthew*, pastel on paper, 310 × 297mm.

he was normal until he was about five, then basically started to regress. He doesn't really respond that much anymore.

So we made some footprints with him and I developed the prints into images to fill a scrapbook of his time at the hospice, which linked in with his parents' travels. They would Skype regularly, so we could share that with Matthew and show them different pages of the scrapbook each time they connected with him online.

We both look up from Judy's journal and sigh...

**JK:** *...I think we need to put the heater back on and boil the kettle.*

**JT:** Yep, I think we need some comforting.

We (Jody and Judy) then spent time making art in response to our conversation, sitting comfortably together at Judy's dining table, with cups of tea to hand, surrounded by art materials. The recording device resting on the piano was soon forgotten, and we were only vaguely aware of each other as we ripped, glued, drew and smoothed our images (Figures 4 and 5).





Figure 4. Judy King, *Art response to conversation*, mixed-media, 310 × 297mm.

Judy wrote next to her image:

“Started with the music sheet – ‘Baby its cold outside’. As I tore the page, on the flip side is a lovely teal coloured drama image, so I had to have that. A lovely box of papers with a black gift paper. This is a gift – sitting in my cosy home art making with Jody. I still have BABY on the flip side of the piece of music and I think of the little baby I spoke of earlier and I use the outer page I’ve torn around the drama masks and a little corner breaks off. I stick this inside, just like Mum’s handprint with the baby’s inside, within the palm of hers. This sets up a theme of holes in the paper, with teal peeping through.

“As I write on the last page of this book, I realise that there’s one part that goes off the page. For two years I’ve carefully trimmed every collage image I’ve used to fit inside this book... and my last image, on the last page peeps out... just a little... almost like a bookmark, but it’s not.”



Figure 5. Jody Thomson, *Art response to conversation*, mixed-media, 297 × 650mm.

Jody wrote:

“Brown paper trees growing off the page. One is actually a squashed circle and inside that a waterfall. Stuck down with blue baby band aids. The climber looks superimposed, going against the flow at the centre of the image. There is a rope, if you look carefully. Most is torn and cut, as I feel torn and cut... imagining losing a child, having a seriously ill child, a child who knew they were dying – my worst nightmare – on the end of a thin rope, frozen in an endless emotional waterfall. The shadow of my own waterfall, of my children losing their father? Am I still abseiling?”

We shared our images with each other, then made an art-and-narrative response, which we read to each other out loud.



Figure 6. Judy King, *Art response to Jody's image and words*, pastel on paper, 310 × 297mm.

This is part of what Judy wrote beside her image: "Her elegant brown paper strips cascading off the end of the page and the central circle at the centre... of togetherness, and I think of her loss... and now I feel sad... the blue band aids, three at a time, the two in the centre make a face... as I smudge across all three shapes, stroking them, forming tendrilled arms reaching around each other."

In Judy's response to Jody's image (Figure 6), she has related her own image to Jody's personal story of losing her young husband to cancer.

**JK:** The art just took over, I couldn't go anywhere else with it. It's about loss.

**JT:** *But you contained the lines... mine go off the page ...*

**JK:** I wanted to contain it for you...

Jody has written and drawn a response to Judy's image (Figure 7), reworking for herself the torn-out shape in Judy's artwork.

"The baby is there, a gift in the space torn out. In the womb-like space... Ben now lives inside his Mum's smudged blue heart. Too fast, too soon. It's sensuous, random, confusing, unpredictable. Where is the voice of the child? So much taken away...

movement taken away, voice and sight. The family watches, witnesses, waits, wants to keep the mark of a hand or foot. Feet that should be walking, hands that should hold and be held... how is it possible to disengage and tolerate this work?"

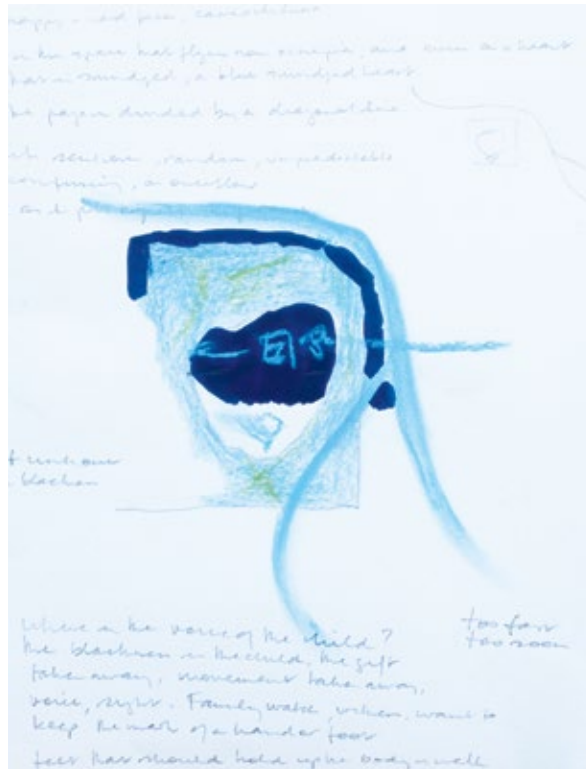


Figure 7. Jody Thomson, *Art response to Judy's image and words*, mixed-media, 100 × 120mm.

Judy and Jody agree to live with their artwork for a few days, then send a written reflection to each other.

Jody writes:

"Torn brown paper stuck down, cut out and stuck again. Stuck, like being held in the nightmare of a dying child, escaping like tendrils off the page, or being stuck in an endless loop. They make bars that I'm looking through to a waterfall, with a single figure abseiling on a thin line, half way down. This view of the waterfall gets smaller across the page, no waterfall at all, gone. Sets of three blue band aids, linking them, holding them down and in the centre, the lonely figure in a blue hat makes a third. Judy told me three stories, stories I have tried to imagine myself into. Impossibly dangerous, and I don't want to even consider holding a dead blue baby, of making blue handprints with a baby, or a child who is about to die. I would want to get down from the fast-flowing waterfall too, moving but frozen, like the images in my mind from her stories. I know what is underneath the stark black and white moonscapes I glued over

the top of the waterfall picture, the things that are there, but I don't want you to see. But they burst out of me when I talked about the image, and tears overwhelmed me for my own losses, normally held in check. Judy sat with me as I cried, reaching out to touch my hand, knowing my story. I drew back, not wanting it to be 'all about me', but maybe it is this layering of experience that allows us to tolerate working with lives, in her case, such young lives, cut short, and families torn, living their lives watching and waiting for death, grasping moments and memories to mark the lives they, and we, must let go of."



Figure 8. Judy King, *Art response to conversation* (detail), 80 × 110mm.

Judy writes:

"Five days after the image making... I scabbled to find a piece of paper to add to the back of this book, trimming it to fit as I have with all the other pages... apart from this last image... and the paper has to be blue, like the baby, and the band aids in Jody's image. Why does the tab stick out? I was so careful to stick other pieces down within the confines of the page. It snuck outside of the boundary, the frame, of the book. My flexibility in my role at the hospice... therapy in the tea room dunking my tea bag, going where they are, both physically and metaphorically. Finding myself walking down the corridor with grandma and not having my break with my colleagues as arranged. The handmade paper that forms the 'tab' seems now to be like a child crawling, shuffling out of the page. It's tightly wrapped,

swaddled, just like little Ben was... so tightly swaddled that he seems to have no arms... almost. That's strange as we worked with his cool little blue hands so intimately whilst his elder brother cradled him.

"Blurring boundaries, the safe space is with me, whether I'm holding a tea mug or paints. The trust and openness and so much of me that make me able to do this work – the ease of talking to a bereaved grandmother and then brother and mother. Some might shy away from the conversation or the intent of making memories through art making. Perhaps nervous of saying the wrong thing, or appearing insensitive... of sitting with the tears, of holding when they need to be held... of saying nothing when that seems right too. That blue figure behind is strong and tall... and needs to be a 'strength' for these families."

#### Endnote

1. All names apart from our own are pseudonyms.

#### Postscript

This iterative art and narrative conversation is an emergent method of enquiry, which Jody is hoping to develop further in her postgraduate research.

We found the idea of publishing this conversation ethically challenging. Casting ourselves as 'co-interviewees' was similarly illuminating. Through many edits of a very long conversation, we found ourselves wanting to soften our words, protect the privacy of vulnerable families, and focus (or not) on our own experience.

*I (Jody) was deeply moved by Judy's words and images, yet surprised at the emotional seepage of my own stories, particularly in reading out loud my response to art-making.*

I (Judy) found myself responding to Jody's image in a very personal way for her. We have been friends for years, as well as supportive colleagues, and I knew so much of her story – perhaps even a little of what was hidden underneath the collaged images she spoke of. When I sat back I was surprised, and worried that I had stepped too far across the line, that I had blurred the boundaries between our friendship and our professional lives. Despite ourselves, our conversation through word and image went deeper.



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