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Transcript of an edited interview with

**Sheryl Blanksby**

STATE LIBRARY OF WESTERN AUSTRALIA — ORAL HISTORY COLLECTION

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### **NOTE TO READER**

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**INTRO:** Death. It's the most inevitable part of life. Some might say it's the only guarantee. But it's also a topic that many people shy away from because it makes us feel uncomfortable, scared or upset. It's often swept under the rug, not acknowledged or talked about, until of course, we come face-to-face with it ourselves. We hope to end this taboo through a series of interviews with many different people from all over Western Australia. We talk to ordinary people about their views on the grief, loss, love and celebration that *is* death and dying. This is a conversation on death.

**SHERYL:** Hi, my name is Sheryl Blanksby and I'm here today to share a story about my beautiful Thomas. I have three beautiful boys. Two of them are with me and one is in my heart. It's a journey that I've been sharing to many about losing a child and moving on. It's not healing, but it's moving forward, I guess; not even moving on, it's moving forward, because life keeps going. So, I'm here to share that journey and just the ups and downs of being a bereaved parent in a society which I can describe as [being] illiterate in terms of grief. Just because of how society [only] wants to see happiness or achievement, like success, rather than talking about pain and loss and grief.

I got pregnant with Thomas after a miscarriage, and it was like one of those surreal moments because it was hard for me to get pregnant. So, the whole journey of getting pregnant was a bit stressful on its own. Straight away, there was a feeling that I was running out of time. That's the only way I can describe it, that I'm running out of time.

So it was like a textbook pregnancy. I didn't gain much weight. All my scans were healthy, the baby is measuring well and [getting] big. I felt that this is the dream. This is what I've been wanting all my life, to have these beautiful children, a husband, a home, a safe place to live in. When we did a six-week check, in my head it was just a normal six-week check, [and we] got to the GP and then somehow the room went quiet. Normally the doctor would be cooing and ahing with the baby, [saying], oh look at you? And he was quiet. I'm like, what's going on? He just said, oh, do you mind doing an ultrasound and coming back in 48 hours to see me? And I'm like, okay, is everything okay? He could feel a mass, but I'm not sure if it's a mass or maybe it's poop or constipation. And I'm like, okay, well, he's not shown me anything to be worried about except a lesion, which I thought was a birth mark. But then my water broke five days before my actual consent for C-section and I went through the whole labour [thinking] I'm going to give birth to this 13-pound baby, oh my God, it's going to wreck me... But it was peaceful. So, I wasn't worried.

But even if I look back now, when I was doing the registration while I was still in the hospital with Thomas next to me and I was doing his birth certificate, I actually ticked the box deceased. I'm like, oh God, like I'm so exhausted. Like I haven't slept, so now I'm like rubbing it off. And then that became that gut instinct again, like someone's going to die in my family. And even at the ultrasound, they were quiet.

I'm like, something's not right because no one's talking to me. All I can remember now is we were booked in to see as a urologist to see [about] getting him diagnosed properly.

**RITA:** How were you at that stage, he's six weeks old...?

**SHERYL:** I kind of didn't want to ask questions because I felt that I won't like what I'm going to hear. It became a coping mechanism. I'll wait [to hear] what you tell me, if you tell me this is nothing [to be worried about] for today, I'll hold on to that. That's today. Because I can go a million miles and I'll be thinking [about] the worst-case scenario. And I'm constantly thinking of my oldest, because my oldest is there already. I'm like, I can't do this to him. I have to be some form of buffer between all this chaos that's going to happen, and him, because he was three at that time. My husband was nonchalant about it. He's like, they're just doing everything they can like, you know, maybe they can remove it. Maybe it's benign. A lot of things are benign... But my gut feeling, [the] mother's instinct, is very strong; that something's not right. And that's when all these terms, Malignant Rhabdoid Tumor, like some pamphlet [was] saying this is what 99 percent [of cases are], based on examples [like] this. And I held onto that 1 percent [chance] that this could be all wrong.

Like, I grew up Catholic. So, I thought, okay, I need to pray. Maybe this is it, and you just need to pray. I shared it on Facebook asking people to pray for my son without giving any details because I was clutching on to that miracle [chance]. I guess [I thought] if everyone's going to pray for him, maybe he'll be okay. He went through his surgery and that was like probably the longest six hours of my life, trying to wait for that phone call.

And Thomas survived the surgery, it [went] wonderfully, [they] did so well, [there was] no blood loss, they got everything out clean, like [there was] nothing in the nodes, [his] lymph nodes were clean. They couldn't find any nodes yet in the chest. So, at that point, it was if he's cancer free. But of course, this kind of cancer starts in a cell, like a really, really tiny cell. And being a baby, you won't know until they start eating again, and they feed the tumor cells. But at that point, that big tumor is out of his body, which is the size of his head, the circumference of his head.

Young babies, they heal really quickly. And they said, oh, we're just going to keep you until we get the diagnosis properly, [until] we get a hundred percent diagnosis [that the tumor was removed]. I'm like, oh, when is that going to be? Because we've been here for so long.

But he did so well, and he got his belly working. When he pooped, I just remember I would share this [news] to Facebook with families all over the world. If I read it now, I cringe, because I'm like, oh my God, I wish I could hold you, like me as my old self, because you know you are lying to yourself. You're pacifying yourself by saying all these positive things at that point when you know deep inside that something's terribly wrong, which was the case. I'm like, oh God, yeah, I remember that. You know what, we're just being positive today. But that meant not entertaining a reality about death.

The shift happened for me when they [told us] the diagnosis, they took us into a room and I'm holding my Thomas and I started shaking before anyone started saying anything to me.

So, our oncologist was there and a palliative nurse and I think another nurse. Then my husband and I were holding Thomas and I started shaking. He was like, are you cold? I was like, I don't know, I'm not, but I'm like, someone needs to get this baby [from] me because he's going to fall out of my hands. So, our nurse, the one looking after him took the baby away, she took him. I was like, thank you. I couldn't stop shaking. My husband had to hold

me, [saying] are you shaking? I was like, I don't know. I literally don't know. And so, they broke the news, and said, yeah, it's a hundred percent now that it's a Malignant Rhabdoid Tumor and it's stage four. He's got two weeks to live. I'm really, really sorry. I wish it was something else. And all I asked was – is he in pain?

Then they said, yes, because the MRI that they did on that day showed tiny nodes in his lungs. I'm like, *oh*. I think his left leg stopped moving, like stopped doing the kicks. So, there's a tumor now growing in his hip bone and I'm like, *oh*. So, they gave me options and [said] we can do treatment. There's no guarantee [he will live] because it's a very aggressive kind of cancer.

Then they started giving me all these things. I said, oh, can you leave me and my husband [alone], we just need to talk about it? Then [they said] yes, of course, of course. So, my husband was like, oh you know, what do you think? Let's go for treatment. And I said, no.

**RITA:** Straight away?

**SHERYL:** Yeah. I said, no. I said, my mum and dad passed away. My mum had breast cancer. She went through all that chemotherapy. She was an adult. She had a terrible, terrible time with it. This is an 11-week-old baby we're talking about. If they're saying [he has] two weeks, I don't want him to be in hospital. I want him to be home. I want him to be somewhere [like that]. I want him to be just doing something, not attached to something, not a tube, nothing like that. Because I want to be able to close my eyes and remember a non-clinical hospital memory of my baby. Obviously, it wasn't an easy decision. We said, can we go home?

I think my main aim was, I don't want him to be in pain, but [also] what about my oldest? What am I going to do with my oldest now? Like how am I going to break it to him? So, all those worries and stuff. So, we prepared [for] the two weeks and I shared it on Facebook. Not the two weeks. I just shared that we're home [and] it is cancer. Then somehow, I shared that, what breaks my heart is, he won't live [past] when he's one [year old]. He won't live to be a one-year-old. So, a community of people, friends, and friends of friends, said [that] we can do a first birthday party for your son.

A first birthday party was organised for us. All I had to do was decide what kind of cake I wanted – oh, chocolate; and what kind of animal? Like, you know, for the flavours. And it's like, oh, an elephant. Because I feel like an elephant is like my son, like he's got good memory. He's very loving, you know? So, it became all about memory-making from that point [on]. A lot of people actually came in to do their part, [saying] oh I want to help you with this, I want to help you with that. And [the] two weeks came. Even in those two weeks, we managed to go to Queensland through the help of Make-A-Wish, PMH, [and from] friends giving us money. I'm like, what do I do? The palliative nurse that we're working with, she said, look, it's okay to accept [the donations]. Because at the end of the day, this is love coming to you, whatever form it is, at this point, it's love. We had this big plan that when Thomas turned two or three, we're going to go to Disney [World] with my oldest. So those were the things [that] we had a bucket of savings for, because we like theme parks, me and my husband, that was one of our things when we were dating. So, these are our plans and

they're just fast-forwarded. The closest we can get to is Queensland instead of Singapore, because we had thought, oh, maybe we should do Singapore, but then – what if he dies in Singapore? I don't want to be doing all that repatriation or anything. So now we'll do Queensland.

It was a lot of love and I think that's why for me, when I look back, I didn't feel alone at that time. It's different now... But before, I didn't feel alone, because I felt that everyone was with us when those two weeks happened, and he was still with us.

I have no regrets because if I close my eyes now, I remember many good memories of us traveling down in Margaret River, or in Queensland, watching sunrises, sunsets, chasing a kangaroo or... being pooped on by birds! Because he was in the bassinet and then a flock of birds [flew past] and I'm like, oh my God, these birds are going to poop [on us], and they did. All these things, they wouldn't have been possible if we were in hospital. My son wouldn't have been able to interact with him because he wouldn't have a [strong] immune system [to do so] and Thomas will be just like, oh, we can't interact, because you've been going to school. As much as my oldest is affected by [Thomas' death], if we went on that path, in my opinion, it would've created much more of a disconnection, not only from his brother, but from me and from his dad, because it would have been much more forceful for us to be with Thomas rather than with him. Rather than as a family unit.

So that is my reasoning. I just didn't want to cause pain at the end of the day. I don't want to cause him pain. At the end of the day, if his life is meant to be short, I want it to be memorable, not only for him or what he can remember and tell me when we meet again, but you know, just for me and my husband and my oldest son. Now with my youngest, we mention him. We have a book [that] some people published, like picture books, of our story. These are [from] my mum's group online. They published this wonderful book with pictures, drawings, they found this illustration artist, and drew Thomas as a normal baby sitting up and crawling, which he's never done. I read that to my youngest [son] if he's interested. My oldest still gets emotional and he gets upset. I tend to just watch his cue on what he can [take] and what he wants when it comes to Thomas and all that. I have stories to tell my youngest that don't involve the hospital. And to me that was very important. Like that was more important than prolonging his life for an unknown future.

**RITA:** You talked earlier about the support that you were given at the time when Thomas was diagnosed and you talked specifically about how there was an online community of people, parents perhaps, who were already dealing with grief who reached out to you?

**SHERYL:** So, meeting other bereaved families, especially mums, bereaved mums, through this online group. It's a UK charity group. Because I shared Thomas' story online and it became sort of viral in some parts of America and South America. Even here, like the Western Australian [newspaper] went to our home and took pictures of us and published his story. So, it went out there and reached this charity in the UK and the lovely lady [there] also lost her daughter, at a much older age as well, not as a baby. So, it's a different thing. She said, do you want to come join? There's other mums and dads and even grandparents were in this group, and they've lost children from this type of cancer.

I'm like, yes, yes please. Initially there was envy when you hear of kids who went to treatment and became well, but then they have so many other medical conditions that they have to live through the rest of their life because of that chemo. [So] I'm like, it's different [for me]. It was what worked for our family. I'm constantly thinking, oh, it must be hard. Like if you lose someone at 18 because of this cancer and you lose someone at three years old and then you lose someone at 23 weeks old. But you know, we get to chat.

Because even with grief, if you join a grief group, it doesn't mean that we are all going to be friends because we are going through the same thing. Grief is so personal that some people will not talk about it, even though they're part of the group, or they will just remember all the pain and suffering, and it feels like they're just trapped in their pain and suffering, and it will take a while to see the good in life again. So that's why it's hard to connect with someone, even though we've [both] lost children. But then I met some wonderful ones whom I met in person when we went traveling. Even now, we don't talk a lot, but then when it's our children's anniversaries, our children's birthdays, we light candles for them. We take pictures of the kids and pictures of our angels. Then we share it whichever way and write a letter. That kind of support is important because it's like, I'm not alone. There're so many kids who die from this cancer. It's nice to be able to like, if I'm really, really low, [to reach out and ask], hey, how are you? Like asking how they're doing.

**RITA:** In some ways that kind of online community is something that you can access at any time when you want, [whereas] as you said, family and friends are absolutely there in the moment when you really need them, and at the point of death and then afterwards for the funeral, but then people go back to life to their normal lives. In some ways it just feels as if you are the only person who hasn't moved on. So I suppose in some ways, has it been a help to be able to tap into this online community and to be able to go over stuff over and over again with people that you don't particularly know?

**SHERYL:** I'd say yes and no, because there's always pros and cons, but more pros for me because there's a mutual understanding of the baseline of what we're feeling. Then, all the other things that we've decided to do. Like some [people] went on to become a social worker, some went on to be an ambulance technician, just because that's how they want to honour their children. But at the baseline of losing someone, going through life without that someone, and having the worst day and then a few good days, and then the worst day, I don't have to explain how that feels. It's understood. It's like a secret language that we have. So, when we talk, we know that it's acknowledged, it's like yeah, I see that today is a hard day. It's much more meaningful when they say, I know it's hard, but I'm here for you. It really means something, I believe that they're here for me. Like it's not just lip service because I know that if I say that to them, that I really mean it, it's not just to leave an offer. And if you need me, I'm here. With this community, it is, especially the ones that I connected with, I know that they're not going to leave me hanging, I guess.

But at the same time, there's that anxiety of [fearing if] what if what happened to [Thomas] happens to my oldest, like it's a constant juggling of those emotions. I think that's when people don't understand that in a life where there's grief like this, it's not linear. I could be okay for months, then something happens that is not even related to anything, and then I'm back to that night when I said goodbye or had to zip [up] that bag. So, that's the bit that's

hard to explain without either scaring the other person or making the person just shut down. Like you can see [them thinking], no I'm not interested, because it's about death now. Because you know that it triggers them.

**RITA:** Looking back, would you have done anything differently?

**SHERYL:** The only thing for me was maybe my phone. Maybe I should have taken [more] pictures or I should [have] dropped the phone and been more present, because in my opinion maybe I was distracted.

Because a lot of people were messaging [me]. Like that phone just buzzed [constantly] and I'm like, oh my God, what is going on? Especially when the story [went] viral, my phone wouldn't stop [ringing] and then I'm constantly messaging people and answering questions and I'm like, maybe I shouldn't have done that? Maybe what I share what I share on social media, what you get is basically what I want to share, instead of feeling compelled to connect with them because they're taking their time [to speak to me]. Like they're giving me their time and effort to message me and check up on Thomas and stuff.

Like the things that I can control, I really want to control them. Like I want him to wear this when he passes away. I want this to happen just before he passed away. And then maybe, if I look back now, I would tell myself, you can't control everything. So just let go of the things that you can't control.

**RITA:** So at that point, had you accepted his death?

**SHERYL:** I started [to]. In the sense that I know that this is going to end, there's going to be a last day for me and him, or a last day for him and the family. But I can only deal with that when it's at night-time and it's just me and him and everyone's asleep. On the day that he passed away, I had a dream and it was a vivid dream. All my family members were at the foot of our bed in our main bedroom, and they're all crying. And I'm like, why are you crying? You're waking the baby!

**RITA:** Sheryl, when you were talking about this, you sound so sure that he was actually going to die on that day, even though he lived way past beyond what the experts had told you. So, what was that [about]?

**SHERYL:** First thing that morning, I thought today is the day. That time the nurse already gave much more comfort medicine, because it was obvious, like the way that my son was breathing, the colour [of his skin], and just how he was. And I just remember [thinking] I feel like I want to cry, but I can't cry. It's like that because there's so many people [there], but then I don't want them to be [outside] because they're family too. I want everyone to leave, but I don't want anyone to leave, like that feeling? Because I just feel that it's as important to them as much as it is to me.

The nurse said that breath is when it's ending, so it's up to you what you want to do. Like, you can dim the light, they're giving suggestions and I'm like, well, it's bedtime. So, just have



night lights and stuff. I can listen to him and I'm like, oh yeah, he's still breathing. He's still breathing.

And then I looked at him and he did a final exhale. As soon as he did the final exhale, I just remember crying. Like howling, not even crying, it's a howling. And then the relief that it ended came. Then the guilt straight away, *quick, quick*. I was like, how could you? How could you feel that relief when that's your son? And quickly I'm like, oh crap, what a terrible way to feel. But [it was] relief [too], because 23 weeks of being a carer of a dying child, it's not a walk in the park, and it's not just him. It's all the other people within the family, their emotions [too]. My oldest, my in-laws, I'm constantly having to think about them as well. So, the fact that I didn't have to think about that when I woke up, that split second before the guilt hit, there was like that *oh* moment. It's as if I was free from that job, if that was a job, and then guilt happened. I'm like, oh my God...

**RITA:** Sheryl, do you think as a society, we are well equipped to deal with that final goodbye and death. Do you think we do it well?

**SHERYL:** No. Being Filipino, we have traditions on the wake and how you do funerals and wakes. And so, I can't do all of that because it's not going to be accepted in Australian regulations, but we managed to bring him back home just the day before the funeral. I invited family members and some friends [over], you know, you can come and view him at home. And people are like, how do you do it? Like that's a corpse. I don't see it. I said, I see him as my baby. He's wearing his pyjamas, he's swaddled, he's got his dummy in, he needs to sleep.

But that was important for me. My husband was luckily onboard with it and I think between me and him, we were very open about all this, having to hold him, having to bring him home. I think it helped him in a way, I hope so, to process grief in a different way, as opposed to what he was brought up with, like the culture and all that from his side of the family, compared to mine.

**RITA:** You talked a little bit earlier about having been brought up as a Catholic in the Philippines. How important do you think that upbringing was in allowing you to be able to deal with Thomas's prognosis [and] his eventual death?

**SHERYL:** Having been brought up as a Catholic in the Philippines where everything happens for a reason is like a foundational kind of thought that is brought up [with you]. God will give you all these tests in life, challenges, but he will give you things that you can handle. So those are the things that help me a lot because I will just say, you know what, this is happening for a reason. As much as I hate that line, that something's happening for a reason, that gave me comfort, that it was out of my control. It was not in my hands. This is happening because there is a higher purpose for it. There's a higher reason, that I won't probably ever understand, but it helped the whole acceptance that he is going to die because he's not mine. He's God's.

I wouldn't have that sort of belief or thinking if I wasn't brought up as a Catholic. And I'm not saying that I'm a heavily devout Catholic, but the principles about having a God and that

when you pass away you go to Heaven, those are fundamentals for me that I believe in and [they] gave me comfort that one day I'll meet him again. Or, he's watching over me and God's looking after him. And so are my other family members who [have] passed away. But that's [the] teaching, the Catholic teaching, that things happen for a reason, it's in God's plan, it's out of your hands, because the story's been written already by God.

In the Philippines, 40 days after the burial... I don't know how to say it. [That's] the belief when they ascend to heaven. So, you gather the whole family, you have a feast, because it's like a celebration that he's finally served the purgatory level and now he's going to be in the Ascension. And as a baby, he doesn't have any sin because he was baptised and all that. So, it was a big thing. I made it a big thing. I had a priest come over so that he can bless the food that we are about to eat so that Thomas can bring it with him. That kind of offering was blessed by the priest. That felt like his actual birthday, in my opinion, for me, because of having to cook, having to prepare and then entertain people and then remember the memories that we've created. I remember having karaoke, like a normal Filipino party. [There was] lots of food and laughter and stories and whatnot.

**RITA:** It's almost like life can carry on, and yet life has irrevocably changed for you.

**SHERYL** Yeah, definitely. Yeah.

**RITA:** Tell me a little bit about the work that you do now, and how that relates back to the experience that you had five years ago with Thomas?

**SHERYL:** So, I am a paediatric nurse and I'm currently in an ICU environment. This has been, I would say, a goal [for me]. When Thomas passed away, I was still in maternity leave and I was working in IT for many, many years. I thought let's do this, let's go back to work [after he dies] and see how it goes. Just pick up the pieces basically. But it never felt the same. Like I [would] come home feeling emptier than I [had left], because I didn't do anything in my opinion [that was] meaningful or substantial.

I'm in this constant [mindset] of honouring Thomas. I just remember, if my day had not been about honouring him in one way, shape or form, then it felt like the day was empty. Like there is nothing. I was drawn to being a paediatric nurse because when we were at PMH at that time, all the nurses were fantastic. I never had one instance of me being doubted, I was the expert of my child. Like when I say, look, I think he's in pain, no one said to me, no, I think he's okay, because he's got meds. They believed me. I was always included. Then they would check up on me when my husband and my oldest come to visit. So, it felt like we were not alone. I'm like, I want to be... like, I could do this.

**RITA:** Did anyone ever say to you, oh, that's a bit morbid, are you sure you want to work with sick babies?

**SHERYL:** No, I would say two out of 10 will always [say], are you sure? Are you really sure? With what my experience was, I feel that it's given me an extra tool in my tool belt, I guess, to deal with that. Because I've been there. So, I know what they're feeling. So, I still love it. I go in and it's hard work, lots of walking, lots of standing, but it feels [like there's]

meaning, like there's a purpose and I think that's important, especially when you're moving forward in a life where you don't have one of your children. It's just unfathomable, to be honest.

My oldest, the other day said, Mum, I know now, I think I understand why you are working with babies. And I'm like, why? [He says], so you can cuddle them, and you can give [them] all the love that you can't give Thomas. And I'm like, oh, you know what, maybe you're right. It just feels fulfilling. Yeah. Does that make sense?

**OUTRO:** Thanks for listening. This interview was recorded on the lands of the Whadjuk Nyungar people, and we pay our respect to their Elders, past, present and emerging. This oral history collection was commissioned by the State Library of Western Australia and produced by Luisa Mitchell from the Centre for Stories. Narration by Luisa Mitchell, editing by Mason Vellios and special thanks to executive producer and interviewer, Rita Alfred-Saggar.

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