

STATE LIBRARY OF WESTERN AUSTRALIA

Transcript of an edited interview with

Amber Dennis

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.

AMBER: I'm Amber and I'm 36 years old and I'm here today to talk about death and dying and grief. I was born with spina bifida and hydrocephalus and I wasn't expected to live past my first birthday, let alone for 36 years. I've always been around death with other patients in hospital [who were] dying, and death doesn't scare me.

RITA: So that prognosis that you were given, that your parents were given, that she's not going to survive her first birthday, she's got all these different things that are actually going to impinge on her quality of life, what was that like growing up with that? Were you and your parents marking off every birthday or did you just suck up the life that you had?

AMBER: We definitely celebrated every birthday, even now at 36, every birthday is a blessing. Every day is a blessing. Every minute is a blessing. My siblings have a great appreciation for life because of me and everybody else in the family also. It really does make you appreciate every moment. So, I feel blessed.

RITA: There must have been difficulties though?

AMBER: Absolutely. I have had over 30 operations, so I have knocked on death's door more than once. My family hates hospitals and they are quite traumatized I suppose, but we try and stay positive and we are thankful that I'm alive. I'm thankful that I'm alive. And my family is really strong. We are very close because of what we've all been through together. And we continue to just stay together as a family and just go through it as a family.

I had quite a good childhood, quite normal for someone in a wheelchair with a disability. I obviously knew that I was different, but I was never treated any different by my family. It's only until I went to school and started getting teased, that is when it started to hit me that, oh, I am different. But my family always told me that's okay. I was very lucky with my parents. They always supported me, gave me all the best therapies, took me to all the appointments. My mum was always on my side and my dad was always working hard to support the family that was at home while I was in the hospital or at appointments. I got to go to mainstream schools. I graduated Year 12 and then went on to university and had a really good education. I'm a big believer in education.

I thought I knew what I wanted to do. It's very interesting in hindsight. I went ahead and got a degree in special needs education because that's how I thought I would help other children with disabilities, but the mainstream jobs are not made out for people with disabilities, unfortunately. I found it physically hard with a wheelchair to get around. People were not

prepared to help me. I pretty much just had to give up that dream because it just wasn't physically possible for me.

It was frustrating. It was devastating. I was married at the time as well, and I was trying to be independent and raise my son and do all these normal things. But I couldn't because the world was just not accessible to me, unfortunately. I think it's when able-bodied people knock me back, when I'm constantly rejected, told that I'm not good enough, told that they can't make something accessible for me and don't help me when I need help. Sometimes we need help and that's okay. That's the hardest part of having a disability, it's constantly having to fight just for your basic human rights just to live in the world.

RITA: When you say death doesn't scare me because you have been there multiple times; you've seen death from a different perspective, haven't you?

AMBER: Absolutely. I am not scared of death because I'm not scared of dying myself, because I've faced it so many times. And for me it seemed peaceful. It seemed like the end of pain, the end of suffering. But then come 2021, [and] my father passed away from a long battle of cancer. Took him about two weeks to slowly pass away. And it was horrific. He wasted away. He was a big six-foot-two man. He was the strongest, most hardworking man I had ever met. He worked so that my mum could be with me at the hospital every single day, every single night. Having him taken away from me and my family was horrific. I wouldn't wish it on anyone and it really changed my whole life and my whole experience of death.

And then two months later, my maternal grandmother passed away unexpectedly. These were two of my biggest supporters. They were part of why I wasn't scared of death. They were part of me being strong and me being positive. So, losing them so close together shook me to the core, absolutely took the rug from underneath me.

RITA: Was it difficult to come to terms with Dad dying?

AMBER: It was, I honestly didn't think he would die, even though I could see him dying before my eyes. I never thought he would die. He was so strong. He was so brave. I was in denial, I suppose. And it wasn't until his last days that I actually realized, wow, he's actually going to die. I'm never going to see him again. I'm never going to get to hug him again. And it was just horrible.

I was definitely grieving for my dad. And then my grandmother ended up in hospital and she was actually supposed to come home. Then the day that she was supposed to come home, she fell into a coma and they said she won't be coming home. So, I hadn't actually seen her while she was in hospital. I rang her and she could still talk a couple of days before. And she said to me, don't come up to the hospital because you can catch a sneeze. And she always, even right up into her last days, was looking after me. I thought, no, I have to see her one last time. So, I went and saw her and I said goodbye. And it was just horrible, so soon after losing my dad. I was just lost. I was depressed. I was really sad.

RITA: And how did you recover from that?

AMBER: Honestly, looking back, I don't know. I found some sort of strength within me and I thought, how would my nanny and my dad want me to continue? Because the rate I was going, I was very depressed. I didn't want to get out of bed. I didn't want to talk to anyone. I didn't want to smile. I just didn't want to leave the house. I just got to a point where, I have a son at home. He's looking at me, looking to me. How do we deal with this together? We've always been a team. And I just got to the point where my dad would always say to me, keep going, Amber, keep going. I thought, you know, I have to keep going for these people that put so much effort into me, bringing me up and had so much faith in me. So, I pulled myself out of the depths of despair and I said, enough is enough. I'm going to keep going.

And then I created a business a few months later after my dad and my nanny passed away. It's called Wheelie Good Perth. I visit businesses throughout Perth and I give them an accessibility audit. I assess their business on all aspects of accessibility because accessibility benefits everyone. And unfortunately, even in 2022, just like the taboo of death and dying, accessibility is not everywhere. It should be. So, I'm here to change that. I have lived experience, 36 years of not being able to get into venues, not being able to access businesses, just because they have decided that accessibility is not important, but it is. I'm here to tell you [that it is].

RITA: And how is that going, Amber?

AMBER: It's going fantastic. I cannot actually believe how well it's gone. It has gone off, the businesses have received me really well. I'm so proud of my business. Every day, I want to get up and get out of bed and go and do the accessibility audits. I want to visit businesses, talk to businesses, talk to people. I love it. It's fantastic.

RITA: Now, when we spoke a couple of months ago, you said to me that actually, if it hadn't been for your dad and nanny passing away, perhaps you wouldn't be in the place you are now?

AMBER: Absolutely. I would not have thought of doing my own business, that's for sure. I would've just plodded along, happy in life just being average, and that's okay. But this really shook me up. It shook me to my core and I'm so glad it did. I think my nanny and my dad would be looking over me going, you go girl. And they would be so proud. That just makes me so happy.

RITA: People often say death is the final goodbye. So, the funeral is the final goodbye. Do you think that that's the case?

AMBER: I don't believe that at all. I believe wherever I go, I carry my nanny and my dad with me, they are with me when I go out and I do my business. They are with me and my son at home. They are constantly with us.

RITA: What do you say to your son, if you have a conversation like that, you know?

AMBER: There's been a couple of times that he's done something or he's gone somewhere and I just turn to him and I say, your pop would be so proud of you right now. And the smile

on my son's face is really precious because he knows that whatever he's done was really important to his pop. So that's how I bring the positivity into it for my son. I like to look at the positive side of things, I always have. And I think that's the way to talk about death and dying.

For me and my son, as it was for me growing up, being around death all the time, he has always known that I was a little bit different and that my life was a little bit more precious because there's always a chance that I could get sick and that death is always around. For me, we've always been open and had discussions that it's not the end, it doesn't mean that I've gone away and I'm not ever coming back. It just means I've moved on to the next part. I think it's important to make it a positive thing. That death is not the end. Death is not scary. Death is not this void that you just go into. No, it's just like life. It's different, you know, everyone's life is different. Everyone's deaths are different and that's okay.

My whole family is really close. They were close before the deaths of my nanny and my dad, but the deaths of my nanny and my dad have made us even closer and that's really helped my son. He can go and stay with my sister or my brother. He can hang out with my mum. He loves his grandma. His grandma is his favorite. And he's her favorite, she tells him. It's quite funny, because she tells all her grandchildren that. I think creating my business out of my loss has shown the rest of my family that there is something good that can come from grief. There is something good that can come from death, you know? I think they see that and it makes them want to keep going. So, it makes me happy.

We need to talk about it more. We need to talk about the grief. We need to talk about the actual experience of death, not just for the person that's dying, but the people around. We need to talk more and we need to have open discussions and for it to be okay, it shouldn't be taboo.

RITA: So, were you able to communicate with Mum and your siblings after Dad passed away? When you talked about your grief, it felt very much as if it was a very personal grief to you. [Did] it just hurt too much to be able to interact with anybody?

AMBER: Yeah, because we spent two weeks pretty much waiting for my dad to pass away and he slowly passed away over two weeks. So, we spent that time all together as a family. After he had finally passed away, we kind of all went our own separate ways for a little while, because we had so much grief to deal with. We needed that time to just deal with our own grief and that's okay. And now a year and a bit later, we've come back together and we can talk about it and we can laugh and we can joke and it's good. We've done really well as a family to stay close, I think.

RITA: Is there a time limit to grief, do you think?

AMBER: No, I'll be grieving forever. I will always miss my dad and my nanny, but that's okay. They were big people in my life. They were huge influences in my life and I love them. I will always love them until the day I die. But I will use that as a positive, that I'll keep going.

Grief does not need to be seen as a negative. It's all perception. I know it feels like there's no light at the end of the tunnel when you are in that grief and you're in that darkness, but just keep going, just take it one day at a time, one shower at a time, one meal at a time. Reach out to those that love you and talk. Just be gentle with yourself and just know that it will end and you will come out the other end, smiling and happier, and it's okay to be down and out for a little while. Give yourself that space and just breathe.

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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