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Transcript of an edited interview with

Sandy Mitchell

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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.

RITA: Sandy, why don't we start with you giving me your name and the reason why you are here today and what you want to talk about?

SANDY: [My name is] Sandy Mitchell. I lost my dad three or so years ago, maybe coming up on four now, to… well, he got dementia and then died. I'm not quite sure whether that was the actual cause of death, but yes, it was sometime prior to that that I really got that he was no longer the man he used to be. Signs started showing probably like, smallish signs, 10 years prior. But the gradual process creeps up and then the last three years were cause for concern and yeah, the last one year was really cause for [concern], like quite [a] disturbing experience for everyone.

RITA: Was he living with you for most of that time?

SANDY: He was living in his own home, but in Balingup, [which is] a small community [with] only 400 people or so. So luckily, we'd just ride down the road and there his house was, and across the road my daughter lived, she rented, and she was able to pop over and cook meals or keep an eye on him, up to a certain point. I would just see him every day and hang out and have a beer with him in the afternoon and talk to him and do a few things with him and make sure everything's okay. But then we'd start [to get] calls from neighbours. "Oh, Don's on the corner. Don's just wearing he's undies over his jeans and you know, I think you better get down here! It's just, something's not right." But being a community, everyone kept an eye out [for him] and always rang me and took him home and knew where he lived.

RITA: Was he independent? Was that a thing, that he wanted to be in his own home?

SANDY: I knew he wouldn't have been happy if we put him somewhere else that wasn't his home. Even when he stayed over – he started staying over the night for the last year at my house every night. I'd pick him up, feed him dinner, put him to bed, give him breakfast and then take him home again. So that transition was a little bit easier for me, just knowing that he wasn't wandering around the middle of the night in his house, freezing cold, thinking he was in a submarine. He had no way of getting warm and it was sometimes below zero [degrees] in Balingup. It gets really cold. I was like, no, we can't do this anymore. The signs were there, you know; leaving the gas on and stuff like that. So, [we're] trying to [get him to] come up for meals at our house, but even when he'd wake up at our house, he was like, where am I? I mean, he was terrifying. He'd look at me and not know [me]; like he mostly knew me, but sometimes he would not know who I was, and he'd accuse me of things, like I was trying to kill him or do something like that. And it just wasn't true. I think he had dementia with Lewy bodies, which is a particularly aggressive type of dementia, [it's] not just

your forgetfulness, [there are] other backstories going on -- there's a bomb [that's] going to go off and, you know, “Shh, be quiet, you know, they're trying to blow us up”, and you had to go along with it. Because if you argued with him, he'd get more upset. So, you had to say, “Okay, Dad, we'll go outside, shall we?” We'd tiptoe outside, then I'd say, “oh, do you want a beer?” Or you know, just change the subject. Then he'd be fine. So, you had to learn the skills to take him away from the trauma, you know? And meanwhile, you are silently traumatizing yourself inside, going, *this is not my dad*. This is someone else completely different. And if he was with us, if he had his faculties, he would hate this. Absolutely be appalled.

RITA: It kind of feels like, listening to you, that actually you'd already started that grieving process even before Dad died?

SANDY: Oh yes, yes. Well, and truly, yeah. I had my three brothers, beautiful supportive brothers, you know, it was so great having brothers or family, siblings, because trying to be a single person dealing with this, I can't even imagine what that would be like. Because you can tell your friends, but it's never the same. There was one incident where my brother Russ went to pick Dad up from the airport. But he wouldn't get in the car with Russ because he didn't recognise him, he just didn't, he thought, you are trying to kidnap me and you've got an ulterior motive, and he was suspicious all the way back to Balingup. Three hours of treating my poor brother like a villain. And Russ is like, come on, Dad, it's me, Russ, you know? I could really see [that] Russ was so shattered by that, not being recognized for the first time in your life. You're in your fifties and your dad can't recognize you and you go back to that child place, where your dad's angry at you and it kind of all comes back, that fear or trauma of being told off as a kid. Like, oh no, Dad's just told me that I'm trying to kill my two granddaughters – and it's just not true.

RITA: Did you ever wish that he would die?

SANDY: I did. Yeah. I remember thinking how nice would it be if Dad just went to bed and we tucked him in and gave him foot massage, he'd calm down. I [would] kiss him goodnight and say, love you dad. He'd say, I love you too. Thank you. You know, he was often lucid in moments, which was like so beautiful, but then I would go, wouldn't it be great if Dad just never woke up? Because I could see how traumatised he was with the whole thing, he'd wake up in the morning and not know how to get dressed and just try to get home. He always wanted to go home. “Will you take me home?” And I'd take him to his house and [he'd say], “Not that home, my home, where I'm normal, where I know things, like my childhood”. It was heartbreaking. Because I couldn't do it, it just didn't exist.

RITA: When do you think the penny dropped that he needed to be somewhere else and that he couldn't manage it and neither could you?

SANDY: When he just started leaving the home at night, apart from like [how] I mentioned, leaving the gas on, because he didn't have any sense of smell and we'd walk in there, and I think, that's gas, it's just totally dangerous. Then I was like, nah, this can't go on. I loved the idea of him being at home. It's the last semblance of normality. I didn't want to take that away from him. But [even] with Maddie across the road doing pills and meals [for him], it still

wasn't enough. He couldn't get away with it anymore and we couldn't get away with it anymore.

The plan was, he was going to go into respite for two weeks while I actually got the other part of the house completely set up for him, like a monitor, so I could have my normal life, but I could just keep an eye and an ear on him at night when he's sleeping. So he wasn't getting up and getting disturbed. I think I had a woman from the home care package [who] said to me, “Don't do that.” And my husband heard it. I kind of didn't, because I was going to give it a red-hot go. I'm going to try everything, probably for myself, but her wisdom and her experience, in a nice way, just said, mm, maybe don't do that. Because she just knew it was going to be so hard. After dad went in for the two weeks, we were getting everything together and then he actually had the biggest meltdown ever.

They thought he was having a stroke. He just couldn't speak. He just looked terrified. And I think he finally looked around and realised he was in that place that he never, ever wanted to be. Dad was someone that always said, look, if I ever get blah, blah, blah, blah, just push me off the cliff or just smother me, you know**,** I don’t want to be around. He was a great candidate for voluntary assisted dying, for sure.

But when you get dementia, I don't think you have a say, unfortunately, you can't actually say, yeah, when I get dementia, I want to go, give me the pill – because you’ve got dementia and you're not lucid and you can't say, I want to sign here. It's the biggest travesty because I reckon those people need it just as much as people that have say, terminal illnesses or pain, you know?

RITA: Like you said earlier, you are so lucky that you've got siblings to share this with and that everyone was on the same page. You know, you seem like an extraordinary family who are able to talk about these things, but we live in a society where actually, death and dying are really difficult topics for people to speak about. I mean in some ways, they're kind of almost the last taboo.

SANDY: We have a fear of upsetting people. I think that's the stem of it. They don't want to bring it up because it might trigger and it might upset you, which is a rational kind of thinking. But the downside of that is, no one talks about it, and you feel like, did that really happen? Am I the only one who feels this? I'm alone here, you know. I felt like no one wanted to talk about it. Was he not worth talking about? You start telling yourself all these other things that just simply aren't true, everyone knows he's so worth talking about, but they just probably didn't want to upset me or make me cry. [So] you go home, you cry about another reason, which is why doesn't anyone want to talk about him?

RITA: When we spoke last, you talked to me about the moment of death with Dad, and I wonder whether you can share that again?

SANDY: Sure. I love that story. It's a strange kind of exaltation that comes with death; the death that is to be expected kind of death, I mean, not just an accidental death. But you know, Dad was in a coma for about five days where he was just breathing steadily. Prior to that, he was thrashing and anxious and moaning and trying to talk and freaking out. It was

really hard to be with him and hold his hand, you know? Because he was so disturbed. So, the last five days were like this transition from that horrible stage into dying, and this lovely kind of tranquillity about that process, where we were all able to get around him and just talk to him – even though they say hearing might be the last thing that goes. Hopefully some of those words went in.

Anyway, this hot, January night, we were in a hospice in the hospital where the family was allowed to be there, or one couple. Sean and I had a fold-out bed next to Dad's and there was a very loud air conditioner on, so I couldn't quite hear his regular breathing. It was like four or five in the morning. These two beautiful nurses came in and I was like, oh yeah, they're just doing his observations to turn him and make sure he is still with us. So, they did that, and I was half dozing. Then they walked out again. I thought, oh yeah, must be all right. [He’s] still going. He's still with us. Don's still with us. So, I was lying there just about to go back to sleep; and something profound hit me in the chest. It was just this little, I can't even say, oh, I heard a noise that triggered this, but I sat bolt upright and went – something’s different. Something is different. And I just raced over to the bed and Dad had his eyes shut. But his mouth open [and] he was looking with his eyes shut. Like he had an alertness, like he was trying to reach out, you know, like that kind of thing.

I went, Dad! And I put my mouth right next to his ear. So, his mouth was right next to my ear. I said, Dad, are you going or something? Words to that effect. I'm here. It's okay. Like, giving him permission to go. And he just went, *ahh...* like this big, long sigh, and it was his last breath. It was like he waited, he called me telepathically. I just feel [that] this is true. Like, they'd done his checks and they were like, no, he's fine, [we’re] out of here. I wasn't leaning on his chest to press the air out or anything like that. It was just this *ahh*, and it was this kind of euphoric sigh. I just knew he died in that moment.

I was so overjoyed because I would've kicked myself if I had missed that moment, I would have been like, oh no, Dad's dead and we weren't holding his hand and [I would have] berated myself. Not that it doesn't matter if you're there or not, I believe, but just personally, I just felt so privileged to have been the one to be there. And it's like he waited for me. He really did. It was so beautiful.

I didn't want to yell out Sean, Sean, Dad's died! You know, it just seemed wrong to do that. So, I just stayed with him for five minutes or so just holding him and it was just so amazing. It was a euphoric moment. I wasn't teary. I was just overjoyed. Somehow, I could feel that passing of him to a much better kind of place, if there is [one].

RITA: It feels like an energy was there?

SANDY: Yeah. It was an energy. It really was. And then when Sean finally came over... We didn't even tell the staff. My brother was sleeping out in the car and [we went] back to the car, got Matt, Matt came over, and then we rang Scott, and he came over, and we were just all around and [saying], oh, look, he's still warm. He's still kind of here, but he wasn't. Then we thought, oh, we better tell them, “Hey, you know...” It was like a whole hour later, you know? [They said], “Oh, is he? Oh, okay."

RITA: [It] felt like in that moment, you were closer to him than you had been for years?

SANDY: Years. [We] really connected. Yeah, you're right. I hadn't felt that love, connecting, two-way love for some time. It was a beautiful parting gift. It meant the world to me. There'd be nothing else that was equal to that, you know?

RITA: Do you believe that there is a good way to die?

SANDY: I do. Look, he went into that coma, as I say, so he probably wasn't conscious of pain. He wasn't even on painkillers, actually. He refused to eat and drink. He went in and he broke his hip – that's right. When he was in the two weeks [respite], he kept standing up and deliberately falling over. I know. They said, no, we can't restrain them. I said, he's going to break his hip – and on the fourth time he finally broke it. Because he was so fit. He fell over and broke it. He had the operation [afterwards], mainly for pain. We knew he wouldn't walk [again], you know, [it was to] get rid of the broken bit. We [thought], we don't know how long Don's going to be with us. He could be here for a year or so more. And so, it seemed crazy. But anyway, [he] came out of the hospital. He just wouldn't drink water. He'd spit it out and just say, no, I'm not drinking your water. I'm not eating your food. I'm getting out of here. I know, there's no doubt, that he had [made] that conscious decision. [He was saying], I don't want to be here. You know, he was saying, eff you to everyone, I want to be gone!

RITA: So, it sounds like he did make his own decision?

SANDY: Oh, he did. There's no doubt in my mind. I was so proud of him, even though his language and his actions [made it hard]. But I thought, well, he's got a fighting spirit. You've got to give him that. He used to be in the SAS. You know, he used to be one of those guys.

RITA: What did it feel like when your brothers came, and you had that hour [with Don]?

SANDY: Great. Just so intimate, just touching, holding his feet and saying things like, oh, Dad's got your feet, Matt, you know? Just talking about life and similarities and playing music and [saying], "Oh, Dad loved this song" and "Yeah, let's put that on". Then we had lots of tears and crying. I remember holding his hand on my head and [it was] like he was stroking me like he did when I was little. It was just so evocative of being a child again. Just reliving that journey of, you know, from the beginning when you were a little baby to the very end when he's *your* baby, you are looking after him, you know? Like the cycle of life. Yeah. It was profound; painful, but profound.

RITA: In terms of the funeral, you say you come from quite a close-knit community, Balingup community, [and] everyone is involved in some way or the other, because they all knew him. [Does] saying goodbye become almost a community thing, that we in cities don't have as much?

SANDY: Yes, that's right. Well, we hired a bus for all the locals to get on and [said], "It's Dad's shout," you know – "That's the last time he is going to be shouting everyone!" All the beer was out at the Bunbury Rose Hotel. They all caught the bus in, and they could drink as much they liked, and then just catch the bus home. I thought, I know Dad would've loved

that, you know? Yeah. He was such a great storyteller, you know. I just loved when Dad would tell a story about his past. He's actually written it [down] in a book, a memoir, *Manji Boy* it's called. And it's just about growing up in Manjimup as a young boy during the war and postwar, it's just brilliant.

RITA: Sandy, how important do you think ritual is in the whole death process?

SANDY: Absolutely important. Ritual with anything, actually. It just makes it real, whether it's celebrating a birthday or anything. If you make a bit of a fuss and put on an extra special this or that, or play songs, it just makes it momentous and therefore present in your life. It wasn't just a passing thing, “Oh, it’s so and so's birthday or anniversary today, that they died, and we didn't do anything, didn't mark the occasion” – it just seems so ordinary somehow. I think as humans, we have a natural leaning towards ritual. Well, I do, maybe a lot of people can't be bothered.

RITA: Do you think modern society has kind of pared that away?

SANDY: I just live with a lot of people that love partying and ritualizing. So, I'm probably not the best person to make an assessment on that because we do that a lot in our lives. I think we do in my own personal life, but yeah, in so many other ways, *no*, we don't have rituals to make momentousness of something that should be actually acknowledged. Like some weddings I go to, people want to skip over their speeches, but to me they are the best part. That's where all the viewpoints come out and they have to flesh out the characters. Even if it's someone I don't know that well, I love hearing what they have to say about them.

RITA: So, having gone through that at the end of life and at the beginning of life, what have you taken away the most from having those two kinds of death experiences?

SANDY: I always want to talk about every facet of it, especially when it's a child, because that's kind of real heavy territory. Which, I have had that experience, [and] I felt like no one wanted to talk about it.

RITA: Yeah. So, tell me a little bit about that then. So, Hugo – he was born premature?

SANDY: No, at eight months. On an ultrasound, they detected that they couldn't see all of his heart and they said, look, we can't really work out what's going on. So, we'll wait for you to have him. He was born three days overdue or whatever. He was born on time. He was a big eight-pound, beautiful boy, crying, responding. So, I was like, oh great! There is nothing wrong with him. Because I thought he might have a hole in the heart or something, like [some] babies do. But then they took him off to have x-rays and then they realized he had a hyperplastic heart condition, which is where you only have two chambers, you need four. They said, look, it's just the worst-case scenario. I mean, it probably isn't now, but back in 1988 it was. They said, there’s nothing we can actually do. It's funny, initially I was relieved, because I was just thinking of him and I just thought [of] this little baby going through heart surgery, [and I thought], no, I don't want that. It's just too traumatic.

But yeah, if they had had a solution, of course I would've probably endured that. But that itself was hard. it was just so numbing, an incredibly numbing experience. Luckily, I had two little kids already and they just made everything so normal, because they were holding him, and they wanted to bring him home and have him as a statue and dress him up and you know... They just bring joy. I was like, oh thank God I've got Maddy and Frank, they just saved my life, you know?

I went home, and he lived for three days. They did say that, they said he will probably live for three days, but it's best you go home and just be surrounded by all your family and friends. And that was good advice. Everyone came over and my dad and my brother built this beautiful – this is Dad, you know, with the dementia, this is the sort of wonderful person he was, he was very creative – and he built this beautiful little coffin, because he knew how to make coffins because his uncle used to do it in Bridgetown. We thought, okay, let's just sit around the fire and paint this coffin and line it with silk and make it all beautiful. It was just cathartic. We kept him in the house. My sister-in-law was a doctor. She said, you don't have to have anyone come and get involved. I didn't want anyone to take him away. He was mine and I had such precious little time with him. No one was going to ruin that. I'm going to be in control of letting go when I'm ready. And it was very strong, clear relief. I thought, yes. Good.

So, we kept him with us and Mum was a nurse, and she knew how to deal with that sort of thing, have him there and keep him good. We planned the funeral and did it all ourselves and drove [him] down to Balingup. Because we knew we were moving down there. So, we thought we want him in the cemetery there, we don't want him somewhere else. It makes sense. It was just beautiful and incredibly sad, and I wouldn't change the way we handled it at all. Lots of crying. [There was] no intervention from anywhere else. I think that we felt like we had control and a handle on it.

RITA: How important is that, to feel that you are in control?

SANDY: Oh, it's paramount. Like if you're going to deal with something, you don't want someone moving in on your territory and changing things forever. Because imagine if someone stepped in and said, no, we've got to take the body now. And you've got to bury him this way and you are not allowed to have your coffin; we're going to have our [one]. You would just be left feeling a right old mess and you really need to get on with it.

Luckily, we conceived three months later, I think. I mean, how amazing was that? I can't believe it, I was so lucky. And that really helped in the grieving process, having another baby, for sure. I mean, it's not going to be that baby, but it's *a* baby. I've had friends that have lost babies and they [say], what do you do? How do you cope? I say, have another one, get back up on the horse if you can! I'm sure that's not stock-standard advice, but that was my advice anyway.

RITA: That is a similar story when people talk about miscarriages, which is that people don't want to upset you, so they don't say anything.

SANDY: Yeah. It's funny, I had a friend who had a stillbirth at six months, or something quite long term, and I had just lost Huey. So, we were quite close. It was really great to be able to

share [that with someone]. She had given birth naturally when it was just going to come out and I made this baby – because of my experience of how people didn't want to get involved really, [and] even though we knew she died – whole baby outfits, like a beautiful layette of all the baby things. And you know, she had a name. The mother's husband thought that it was inflammatory or, I don't know what word [to use], but she was touched. And she just thanked me so much for being so involved and acknowledging this child, you know. It really was there, and it really was a baby, and her loss was real.

RITA: Did you think that the grieving process for Dad was different from the grieving process with Huey? Did you feel that people around you, not necessarily your family, but people around you reacted differently?

SANDY: Yes. They were way happier to talk about Don, because he was such a colourful character and he had such a big presence, [and] because they had known him for so long. Yeah, it was easy for people to talk about Don all the time. So, I didn't have any like, oh, no one's acknowledging or wanting to bring up my dad. That was never a problem. But with Huey, babies, I don't know, it's kind of all taboo somehow, you know? It's more unlikely [that] a baby dies than it is a person of old age. You know, with Huey, we only had three days. I remember having a little bath with him and little moments of incredible intimacy. So, with Dad, I was trying to make him stay and live with us. I thought, we can cope with this.

RITA: Did you feel that you actually had time to grieve while he was living?

SANDY: Yeah. Well, I would come home, and I debriefed all the time. I think my debriefing was Sean and friends. God bless them for listening. It was a very intense debriefing for a few years there, that a lot of people had to put up with, but they were great empathetic friends. I think through talking, [that] was my main [grieving process]. And my friend Lisa, she's got a very elderly mum and we just talked a hell of a lot about, try this, try that, and supporting one another.

RITA: Do you think families get enough support?

SANDY: I don't think there's any such thing as too much support. I think you can always just say, no, I've had enough of this kind of talk. I need to go for a run or [whatever]. But I just think you can't hurt someone by always asking the question, let's talk about this, and how do you feel? It's so valuable to have that. Or just being lucky enough to be in a family where you feel comfortable with someone who's going to actually listen.

I think connecting with people more, because you just don't know when they won't be there anymore, and you just want to make sure the colour of conversation or interaction you have with someone is really like a hundred percent and not crappy. Or, if it's crappy, go back and reiterate and just say, I'm sorry. You know, like, it doesn't matter how tiny it is or insignificant, it actually helps you deal with, say, if someone does suddenly die, you just know in your heart that the last conversation you may have had with them was a truthful, total one, rather than a half-hearted one. I mean, you can't be like this all the time, it's idealistic to be that way, but just be conscious of that. Try and connect more with people.

RITA: So, did Mum die a long time ago?

SANDY: She did. She died 30 years ago of cancer. Dad and Mum were the love of each other's lives. Dad was so brave. He was in Perth when Mum died. So, he thought, no, I'm not going to sit at home here. I'm going to go into Balingup where Sean and I were with our little kids. I'm going to make a life for me. He loved Balingup. He was a country boy. And he made his own friends straight away, you know? He bought microlight airplanes and flew them around and bought a motor bike. He reverted to being a bogan teenager. He was hilarious. Yeah, he did some stuff that Mum probably wouldn't have approved of, but he was having fun and he was living life and sucking the marrow out of life and that was just Dad all over.

That was a great thing about Mum. She had a much more tempering effect on him, but he needed that too, because if he never met her, I think he would've kind of gotten into a bit of trouble somehow. So, they both were great for each other. Like he was really exciting and imaginative, but she loved that about him.

RITA: Was that goodbye harder?

SANDY: For my mum? Oh yeah. I talk to my mum every day and I haven't even touched on Mum – it's funny, isn't it? Every day I go to this place in my garden – well, not every day, but nearly – whenever something's bothering me or I'm worried, I just say a little kind of prayer, I suppose, to Mum, and just say, can you please look out for such and such? That straight away makes me feel [like], “Right. Great. That's going to be okay now”. I know there's no rhyme or reason as to why that should work, but it just does for me. I love it.

She was a lovely, beautiful nurse, a listener, a kind, funny person, and was a great sewer and taught me everything I know about dressmaking. I think of her every day; her photos right above my sewing machine, and whenever I'm making something really important, I always look at her and go, Mum, you know what to do. Which means she's going to make it go okay and I'm going to take the right path when I make cutting decisions and stuff. And it works, you know! Or [if] I'm looking for the missing button, [I’ll say], “Mum, help me find the missing buttons, there’s three, I need four”. It'll turn up. It's amazing how often that's happened.

I have great fun with her. She's just alive in my soul every day. She's such a big part of my life, even though I was 30 when she died. I'm 61 now. But yeah, the way they loved each other was a beautiful thing. That's why our family was so lucky to grow up under their parentage, because they never fought or if they did, they kept it away from us. They had their own private fights and we didn't know about it. They were a very united front and they were really great in making us independent and learning the hard way, and just getting out there and making mistakes, you know? They just were the perfect balance for each other and for us too. So hopefully some of that's rubbed off on our kids, you know?

She's just so with me now that I don't feel like it's a death. She's with me. I talk to her, I communicate [with her]. I know how she thinks, I've got a really strong recall of who and how she was. I love bringing them to life and talking about things they said and did, because

people love it. You know, when you bring up someone's name, [like] a friend of ours that died prematurely – oh, I remember when she [would] lalala, and she said this – and everyone just laughs and goes, oh God, wasn't she great, you know? It just keeps the memory living longer.

You know, there will be that point in time when no one knows who you or I are and to even have a conversation anymore, like it's just the ever-evolving thing that happens. But yeah, while I'm alive, I'll try and keep everyone alive for as long as I can, anyway!

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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