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Transcript of an edited interview with

Marilyn Metta

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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.

MARILYN: My name is Marilyn Metta. I am a trauma counsellor. I work at the Metis Centre as a trauma counsellor with families and particularly young children from culturally and linguistically diverse backgrounds. I've been doing this sort of work for the last 20 years. I also work for a not-for-profit organisation, Metamorphosis, and our focus is really working with children and young people from refugee backgrounds who are also stateless and providing [them with] access to education. So, I guess I work with trauma a lot, that's my bread and butter. I have been really interested and fascinated and also engaged with death and dying for a very long time, since I was very, very young.

RITA: As you were growing up, [you said] death and dying was very much part of your whole environment. What do you mean by that?

MARILYN: I grew up with a mum who I guess I would say had a lot of trauma. My mum was a very traumatised woman. She was given away as a baby and was terribly abused. Growing up with Mum, and we probably now know that she had depression throughout her life, a very common theme in my mum's stories and storytelling – she was an amazing storyteller, so we grew up with stories, really imbued with stories – and dying was a big part of Mum's story. She was always talking about when she dies and she had always planned her death and how she wanted to die and [was] really quite fascinated. It was only later on, when I became an adult and I trained to be a counsellor, that I understood that a lot of her narratives around death and dying were very much impacted by her experience of trauma. I grew up with a lot of that. And then I guess when I was a teenager, I encountered Buddhism and some of the Buddhist teachings around life as a sort of a meditation on death and the relationship around how we live our life and how death is imminent and unpredictable.

RITA: Do you think within your cultural context, you're Chinese Malay, speaking about death is part and parcel of life, or was that really quite an uncommon thing, and it was just something that you grew up with because you had a mum who'd gone through trauma?

MARILYN: You know, people have big events and celebrations and festivals around death. I guess that's also the visibility of it. And with Mum, I guess she often talked about up death, as with I think a lot of people who are experiencing depression and trauma, often death appeared to be an escape, somewhere better than the living. And I think that's a big part of my mother's story and growing up. I found Mum's preparation for death [too], you know, she bought her burial plot decades ago and she had really given us very clear instructions on how to manage her death and her afterlife. That is quite unusual, because I think in a lot of Chinese cultures, death is quite a taboo topic. As much as it is visible, I think fear of death is common in all cultures. I think it's definitely [the case] in the Malaysian Chinese culture,

where death is obviously something that people are afraid of. But there's also huge preparation around people wanting to be buried together. So, the preparation around that, the rituals around that, I think those are really... I'm only sort of beginning to really appreciate how much those rituals are important in grieving, in helping us grieve when we do lose someone.

RITA: So, let's talk a little bit about the experience that you went through with Mum at the end of her life, because in some ways that was relatively an uncommon experience and something very much that she wanted.

MARILYN: About five years ago... So, my mum lives in Malaysia and my sister and I live in Perth and then I've got a second sister who lives in Malaysia as well. We just got a call one day from a friend of my mother's, to say that Mum was in hospital. She had had a suspected heart attack and she was unconscious. My sister and I flew back. We took the first flight back to Singapore and got a taxi through to the Causeway to Johor Bahru, which is where Mum was living. And we got to the hospital and Mum was unconscious. It was obviously very sudden, but Mum had an ongoing long-term issue with high blood pressure and high cholesterol, which she self-medicated. It took a few days for us to get [there] and Mum was in a public hospital system, which makes things a bit complicated. They suspected heart attack, but it took about three days before they could scan her brain to realize that she's had a massive stroke, massive haemorrhage in the brain, and the prospect of her coming back to consciousness was really minimal.

Mum had always left very clear instructions on how she does not want to be left in vegetative state. Mum is a very strong, powerful woman. And she's left the instructions with me. After her death, my older sister and I have had conversations about why Mum left me with the task of how she was going to die. I guess on some level, she knew that I was going to be the only one who could do it. So we were in that situation, we had to wait, and Mum was left in that state for 12 days and every single one of those 12 days, I had Mum next to my ear saying, "Remember what I say to you?" And even if Mum hadn't left the instruction, knowing who Mum is, that would be a very, very distressing place to be, but we had to. This is part of the context of the Malaysian Chinese culture, where people in that state are left in the vegetative state for years. That's a part of people not wanting to let go. That's, in a really strange way, but also understandable way, how they show love; they want to prolong [their] life as long as possible. And that might be the wishes for some people, [but] that is definitely not Mum's wishes. So that was very clear, but we had to make sure that everybody came to say goodbye and we had to make sure that we had convinced everybody that everything had been done and there was no way out. So that was a very interesting process to witness and to navigate.

RITA: Were you ever asked by the hospital authorities to consider switching off the machines?

MARILYN: No. Malaysia doesn't have euthanasia. They don't have laws around that. For the days leading up to the end, I had closed communication with the doctor and I was told very clearly that this is against the law, we cannot do that. But I then realized that I had to advocate for Mum in saying that I am not going to leave her in this situation. This is against

her wish and that we need to let her go. So, she was on oxygen and the doctor eventually came to me and said, "Look, we can't do it because it's against the law. But if you feel that it's time to let her go, you are going to have to be the person to take the oxygen mask off and we will give you some private space to do that."

RITA: How did that feel to be in control? I mean, in one way you can say that theoretically you think you can do that and that that's Mum's wishes, but to *physically actually* be the person who does that...?

MARILYN: I mean it's emotional just even thinking about that. It's heart wrenching. It was sort of a whole mix of feelings that I am the person [who] is going to be ultimately ending Mum's life. But what was even clearer and more powerful was that I was doing the right thing and there was no doubt around that. Once I sort of come to that moment, I felt this sense of calm. I felt a sense of relief, and grief and sadness, but the relief was palpable. And then we had, I can't remember how many hours then, and [we] just sort of sat with Mum and everyone had a turn to say goodbye and to be there with Mum until she took her last breath; it was quite a few hours later. She was made comfortable. She had morphine to make those last few hours and moments comfortable. So, we knew that she was okay.

RITA: But you did have family members come and say goodbye. They knew what you were going to do. What was the reaction of other family members? Were they supportive?

MARILYN: I think so. I think they knew that I had the authority, I don't know whether that's the right word, to make decisions for her. But I did set everyone down and I did talk to them about Mum's wishes and about how Mum would have hated every day of those 12 days being left in [a vegetative state]. I guess I reminded them who Mum was and what was important to her. And I think that really helped. It was also of course really heartbreaking and very sad, but I think everyone found peace because we knew what she would have wanted. I think that was very clear.

RITA: Did you feel her presence at that stage?

MARILYN: Yes. I think it was like she was there but she was sort of in the corner of the room. I knew that at some point she wasn't there in the body anymore. It was just a physical form. But Mum was always with me, Mum is still with me and her presence, she's got a larger-than-life personality, I know that it's always going to be there. In fact, it's probably stronger since her passing. I have a photo of her in a sort of a little mini altar that I light a candle for her every morning, every night. And so, she's very much present in my life.

RITA: You've talked before about the importance of rituals and anniversaries and how important that is. You're coming up to Mum's fifth anniversary sometime this month. Describe to me how you feel now, five years later?

MARILYN: I feel a sense of blessing. I feel very blessed to have had the life that we've had with Mum. I did my PhD thesis on my mother's life and I feel that I really understood and know the person that she was. That is a really beautiful gift. I think that knowing her and knowing her so intimately has really helped in my grief, but I feel like I was able to bring her

so intimately close to me. It's the same thing with my sister and my kids. They've had such a beautiful relationship with her and I feel that five years on, it is a new phase in a way. I've actually been talking to my sister about this because Mum was an extraordinary cook, amazing cook. I thought, well, I think what I really would love to do for her is to do like a cookbook, but with stories of the heritage and the stories around all the dishes that she's created and crafted over the years.

We really want my sister and I, and hopefully the kids as well, to come on a road trip back to her hometown through Malaysia and start putting this together. I think that would be a really beautiful tribute to her. And also I think, something that I want future generation to have of her, and to taste her cooking, because she is a legendary. She's such an amazing storyteller. She's got this really, really amazing voice. Very funny. So, I want her stories and hopefully part of that voice to be captured, along with her cooking and her dishes.

RITA: Do you think as a society we introduce death early enough to our children and do we talk about death enough?

MARILYN: I don't think nearly enough. I think that we are very protective over kids around death and grief and anything that is traumatic. And I think that we're doing them a disfavor. I think that it is such a big part of life and we really need to equip children and young people around death and dying. I think a big part of it is because we protect ourselves from it. [Yet] so much healing and strength can come from talking about the most painful things, including death and dying.

RITA: That must be some of the work that you do in your work as a trauma counselor. With the migrant and refugee experience, death must be part and parcel of their everyday lived experience?

MARILYN: Absolutely. Especially people who have been impacted by trauma, whether it's true violence, abuse growing up or the refugee journey where they were persecuted, where violence and death was such a big part of their life. I think for a lot of families that I work with, and this is obviously a very common story with a lot of migrant families through the generations, is we often have parents who have been through and been impacted by trauma [who are] trying to protect their own children from it. So, they seal off that story and park it deep down in the dungeon. And with all their best intentions, thinking that that's the best way to protect the future generations. But we know now, with intergenerational trauma and epigenetics and how trauma gets passed down, we don't deal with it.

So, a lot of my work's really creating the safe space for people to start unpacking the past trauma and giving people the tools, that's such an important part of recovery. And this is not something that is unique to migrant communities or refugee communities. Your average Australian family has a huge history of trauma from the convict history, from war. We know that our First Nation people have intergenerational trauma that was impacted by colonisation. It is something that touches many families. I think that in many ways, because we're so uncomfortable talking about trauma, death and dying becomes very much part of that difficulty. I think we are definitely getting better at that, but there's a lot more we can do.

Just having conversations and normalising these kinds of conversations I think is a really big part of us being more comfortable talking about it.

RITA: You're right about migrants and refugees wanting to put the past behind them if you like, "this is a fresh start". So, it is quite normal, Isn't it, to kind of say that was me and my identity before, but now I'm in a place where I can go forward?

MARILYN: Yeah, look, I think it's very, very human. You know, I think a very human response, but I think when we have, and part of that starting new life means that we have to tuck away that lived experience that's when it becomes problematic, because until we deal with that trauma, it will continue to have that impact on us and on mental health, physical health and that sort of stuff. It also impacts relationships going down the track. I think that we can start anew, but part of that starting anew is to be able to deal with our past and that it can be done, and people can go on and, and live really, really beautiful lives, but we have to be supported actually, because we can't do this on our own. We need the support system to help us do this. I've worked with young people where parents start to do that and the transformative power of each generation taking responsibility dealing with their own trauma. It just means that it opens up opportunities for the next generation to be less impacted. But also then if they are, then it's okay to talk about it. It's okay to get support and get help. I think that we need to get better doing that and be more comfortable at doing that.

RITA: You mentioned that your daughter was with you throughout the process, throughout the 12 days and the decision to take the oxygen mask from Mum's face and say goodbye to her and allow her to go. How old was she?

MARILYN: Jess would've been 16, 15, 16?

RITA: It's an age where the impact of such a powerful display of life and death would've been so strong. How did she deal with that? How did you and her talk through that trauma? Was it trauma?

MARILYN: It is kind of a trauma, but also it is Jesse's first encounter up close and personal with death and dying. That moment where we say goodbye to Mum and her *Popo*, and she was really close to [her]. The first thing that Jesse came to me and said was, Mum, don't you worry, I've got your back. I think in that moment I understood that she understood what I was doing. It was a very emotional moment. I think that was so important for Jess to be there because that's life, that is so important. To know that each generation, we have that responsibility, but we need to talk about what we want with our family, you know? I think that conversation's so important and I know it's scary to have this conversation, but it really brings us closer. I know now that my kids are very clear about how I feel and what I want, and that clarity was just there. For Jesse that is a moment in time where she's able to be so close to it and to understand it and to feel the whole range of emotion that comes with losing someone close [to you].

RITA: So I'm going to take you back a little bit, because you've had your own experience with near death when you were bringing a life into being. Tell me a little bit about that?

MARILYN: Yeah. So that was Jesse! I was pregnant with Jesse and Jesse's 20 now. So, this goes back that long ago now. I was sort of about 38 weeks [pregnant] and had just gone home with a massive headache and realized that I had preeclampsia, very, very high blood pressure, and was rushed to hospital. Because I had preeclampsia and it was my first birth, things got very frantic and messy. Jess was born very, very quickly. It was a super quick birth. I think everything happened within an hour and because it was very a fast delivery and because I had very high blood pressure, which causes retained placenta, I had massive blood loss. I remember Jesse being born and holding Jesse in my arms and then starting to feel really dizzy. I sort of realized that I am not feeling very well. And I remember passing Jesse to someone [else] and then passing out.

In the middle of that, just before I lost consciousness, I just remember the room suddenly filled with a rush of people, doctors, nurses, and then I sort of passed out and lost consciousness. What happened was, I started spinning. It was as if I was, all of me, all of my consciousness, was in this tiny little dot and I was spinning. And then *snap*, there was a clear snap, and I was just floating. It was white around me. It was like I was a little star in space, just floating. And in that moment, I realised I had died. It was so beautiful. It was so peaceful. It was like all of me was in this tiny little dot and I don't know how long I was floating in this place for...

Bliss. I have never experienced that level of bliss again. I was floating there and then I suddenly remembered that I had just given birth to my baby. Suddenly the rush of [thinking], "Oh my God, I can't leave my baby without a mother." I had to get back to her. It was just this disorienting thing.

But I remember thinking to myself at that moment, I wonder if I ever made it back, whether I [will] remember this. The next moment I woke up in the hospital really, really unwell. I had lost nearly four litres of blood. They tried for many hours to stop the bleeding, they couldn't [at first], but they eventually managed. I woke up in the hospital very, very sick. I could barely move, but the moment that I woke up, I remembered *everything*. It was a life changing moment. It continued to be, and the last 20 years, I've felt like I'm on borrowed time. I feel like I had a second chance to... I came back because I could not leave my newborn child. You know, that maternal instinct was clearly so strong and so powerful. There I was, so blissed out, I could stay there forever. I came back and had this second chance in life, and I feel it has changed the way I think about dying.

RITA: So, you are no longer afraid of dying?

MARILYN: Yeah. I'm not sure if I was afraid of dying, but I certainly didn't understand, having that sort of lived experience definitely brought a completely different dimension to my understanding of dying and death. It's something that I'm not afraid of. It's definitely made me more appreciative of life and living. It's given me a spaciousness around the relationship between life and death. I think that it's not a clear-cut black and white thing, that it's a continuum. I think that's a beautiful thing.

RITA: How did other people react to that complete death experience where they'd almost lost you, and then you were back?

MARILYN: Yeah. Terrifying. My mother was actually in Perth at that time, [she] came to be with me and to do the confinement thing. I had planned a home birth and it was all very terrifying for everybody. But I realised that when I wanted to talk about that experience, people couldn't believe it. [They'd say] oh no, you were just on gas or something. I sort of just kept it [to myself]. It was a very sacred experience for me. Even though other people couldn't understand it, it was just there, it was my reality and it was my experience. I had written about it afterwards. It's just something that's very real and very sacred to me. I have not shared that story very often.

I had just given birth, given life to my child, and we know that through history so many women died during childbirth. I think that it is an important part of us understanding life, dying and death. I feel really blessed to have had that experience, to be able to have come back and to be able to raise Jesse, and I went on and had another son. It was one of the most beautiful experiences I will ever have.

RITA: Do you think that people treated you differently?

MARILYN: At that point in time, very few people. In fact, no one could understand that experience. So, it wasn't probably taken very seriously. I think they obviously understood how close I was to dying. But you know, then I became a mum, so the excitement of all of that and the craziness of that took over.

My mother especially, it was traumatic for her, because she had worried the minute I had decided to have a home birth and she tried really hard [to stop it], [but] I was my mother's daughter. I was incredibly determined and stubborn. I know that that would have been a very, very traumatic experience for her. She continued to remind me [of this] for many years later.

RITA: So could you ever talk to her about that moment of bliss?

MARILYN: I don't think I did. Because I speak to my mum in my mother tongue, in Hokkien, and it was very hard. My Hokkien is not terribly sophisticated. It was very hard, and I think I realised how traumatic it was for her, that I couldn't really go there. But I wish I had told her more about how blissful it was. I think in many ways, Mum was very spiritual. She is someone who isn't afraid of dying or death because she had always believed that that place after death was a peaceful place, [it] was something that she had thought a lot about during her life. She had a life full of suffering and trauma. So, she would dream about going to this special place after death where the suffering would end. I think that in many ways, she and I sort of shared that. I very much believe that she is in a better place.

RITA: Let's just talk a little bit about that spirituality and the rituals and the traditions and people's beliefs and how people might say, I don't believe in anything after life and I'm an atheist or I'm an agnostic. And yet, at the moment when people are faced with their own mortality, [their] spirituality, maybe religion, becomes actually quite an important thing. Do you find that in the work that you do with people, the talks that you have, and also in your own life experience, that spirituality is something that we revisit over and over again as we go through [our] lifecycle?

MARILYN: Look, that's a very big question, isn't it? I use spirituality because I think that it's something that everybody has access to – an essence, it's a belief, it's faith. You don't have to be religious. You don't have to have a faith to have access to that. It's all around us, it's the universe, you know? I know people who don't have a religion but have a special connection. Spirituality could be your connection to Earth, could be your connection to forest, to the river. I think that we need to have a much more expansive understanding of spirituality. It's something that we find peace in and that place is what people call on in time of crisis, in that moment of dying. I think we call on what gives us peace and whatever that is, [it] means different things and feels like different things to different people. And I think it is that moment of holding something that gives us comfort and faith, whatever that might be. And it doesn't necessarily have to be religion or faith.

RITA: In a modern world where we've, in some ways, banished death – we all live longer, we live younger, 40 is the new 20 – how does spirituality and acceptance of death fit into that, do you think?

MARILYN: You know, we've got great opportunity with longevity, but also with a lot more knowledge and understanding, or access to understanding, I think that we've got opportunities to live life more meaningfully and with that, have opportunity to develop our understanding, choices, agency and autonomy around death and dying. That is so important, [particularly] for women to have choices around how they want to give birth and how they want to [do] all of that, pregnancy, birth, childbirth. I think everyone needs to have autonomy and agency around choices, around how we die. That's very, very important. And I think we are just beginning to have that kind of conversation with prolonged longevity. It just means that we have a much longer time to contend with our bodies and how we live in this body, how we look after this body, how we heal this body, how we take care of this body. I think all of that's part and parcel of that bigger conversation around death and dying.

RITA: Do you think that we devote any of that energy to talking about mental health in regard to our own mortality or the people around us that we love and lose?

MARILYN: No. I think that that's a big white elephant in the room, in many cases. I think that for a lot of people the idea of death and dying, whether it's experienced as a loss, or protecting other people from our own illness, ill health or death, is something that we as a society don't navigate really well, and it's a big part of mental health. I think the more we are able to talk about the distress that we feel every day and have ways to manage that better in terms of recovery, in terms of healing, in terms of actually navigating when life will throw us curve balls that we don't expect, and that we can cope with it. Just like we can cope with unexpected death, we can cope with unexpected ill health, whether it's mental or physical, and that we can get through it. We just need to have the support system in place and we can reach out for help. That's really important. I think as a society everyone has a role to play, as a family member, as a parent, as a child, as a friend, a colleague. I think the more we can have conversations like that and normalise that, so that we don't feel uncomfortable broaching that topic, I think we'll be better off for it.

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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