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Transcript of an edited interview with

Leanne O'Shea

STATE LIBRARY OF WESTERN AUSTRALIA — ORAL HISTORY COLLECTION

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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.

LEANNE: My name is Leanne O'Shea, and I am the Director of the Southwest Grief and Loss Centre that's based in Bunbury, and I have been working in the end of life and grief space now for well over five years, not only in my own private practice, but also with the Busselton hospice, the health department, the Motor Neuron Association, developing a compassionate community program. I'm here today to really share and have a conversation about the importance of stepping into the discomfort of death and dying and grief and bereavement, to find comfort in the importance of mourning and the importance of allowing the emotions of grief to be a part of the process of loss.

RITA: Why was it important for you to set up the Centre?

LEANNE: So, through my counselling studies and my counselling practice, what I came to realise is that in everyone's story, there was an element of loss, but they didn't understand that they were grieving. I saw that nearly every client was grieving. Grieving the loss of a job; grieving the loss of a relationship; grieving the loss of their own independence or self-worth; grieving the loss of a relationship breakdown in the workplace; grieving loss of their health. So, you can see very quickly, that grief is a very important response to loss. So, I started to see that we needed to re-educate our community on grief and why grief is a very important response and if we avoid it, then it creates many more problems, both physically, emotionally, and mentally. I started to see the importance of this work. No one was doing it, no one was having the conversation and it was a conversation that a lot of people would prefer to avoid.

RITA: So, how do people make that journey to recognising that they need to deal with their grief perhaps and they need to come to somebody like you or the Centre?

LEANNE: They start to recognise that they're not coping and that their daily life is deteriorating through their own mental health or their emotional and physical wellbeing. So, they think they're coming for help for their inability to cope and feel good, because we live in a society where we must just feel good all the time and we've just got to get on with it. And if we are not busy, then we are not recognised to be living our best life, but we actually need to reverse that. We need to give ourselves permission to slow down and acknowledge the sorrows of life. So, what I share a lot is that when we step into the discomfort and give ourselves permission to step into the discomfort of life, we will always find comfort.

RITA: So, we often talk about death as being the last taboo. And yet death is something that is an inevitability for all of us, but something that we find very difficult as a modern culture to be able to talk about openly and freely.

LEANNE: Oh, absolutely. But every time that I've held a forum or a community workshop, they're not sure why they're attending. We love talking about life, but we don't want to talk about death and dying. It's something that I share a lot, that in one's lifetime, we will experience a thousand sorrows and a thousand joys. We can't have one without the other. They go together.

RITA: But most people don't really think that, do they, Leanne? Most people kind of think, well, I'm living life, I'm busy, living longer, younger, stronger, all of those things. And none of those things are bad. But inevitably death awaits all of us, and we have a lot of support at the beginning for life, but there's not really, in terms of our social structures, support at the end of the life. Do you think that's a modern phenomenon?

LEANNE: I believe that we need to go back to a community that supports each other. I shouldn't necessarily be in a job. It should be our community's responsibility. It's a human role to come together and support each other. Generations ago we knew our neighbours. We knew our community members. Even I remember as a little girl the lollipop lady, the post office, the corner store, our neighbours, we all knew each other and you felt like you belonged, and you felt like you were well looked after. But we live in a community now where we're very disconnected. I think we need to re-educate [people on] the importance of community, that it's community that support each other in times of need and we all need that throughout our timelines. So, I value the work of compassionate communities because I think we need to come back to that human need and that [need] is connection.

I think compassionate communities is about re-educating our community about how to support someone who is dying, caring, or grieving and how to ask for help. I don't think we know how to ask for help anymore. Even if we are a part of a smaller culture, be it the culture of your cricket club, the culture of your ethnic background, the culture of your workplace, where you feel comfortable, where you actually feel valued in what you love and who you are and what you contribute back to the community. So, if it is a football club and they know what to do when a member dies or becomes terminally ill, how beautiful that they've come together and supported each other in a way that's very caring and compassionate. And they would carry that burden of wanting to do something, but not quite sure what to do. When we don't know what to do, we stay away. We cross the road to avoid the conversation because we feel helpless. Well, let's develop a community where they feel empowered. I have seen it living in small communities where they do come together and make a difference. I've seen it strengthen a community because they feel like they belong. So that compassionate community just grows stronger and stronger and stronger because they've seen the evidence of what it looks like to actually come out and support somebody.

RITA: And we've seen that with say church communities or migrant communities where they do feel that they need to support each other because the outside world perhaps doesn't get what they need. How important do you think the role of rituals and tradition is in supporting grief and death and loss?

LEANNE: I advocate for this a lot because we need time to grieve. When we have time to grieve, we identify who we are in our mourning process. When we are mourning, naturally rituals become a part of that. Rituals are very much a part of many other cultures around the

world, and we see the difference that they make, not only at end of life, I truly believe that the grieving process is so important to acknowledge and commence before death. So there really is a pre- and post-grief. I see it all the time with the clients that I work for who are at end of life and the conversations that I facilitate with the family members. They start to identify that they're already grieving now.

A lot of people now naturally think that grieving is a mental health condition. It is not, absolutely it is not. There are risks associated with grief if the right support isn't there. But again, in our culture, we don't have time for emotions. We see the emotions of when life is difficult, that they are *negative* emotions. There're no positive or negative emotions. They all have an important part to play. It's how we actually respond to them.

RITA: Well, part of modern culture, I suppose, is that there is this strong emphasis on personal space and privacy which other cultures maybe don't really experience to that degree. So many people might say, look, I don't know what to say, I don't know whether I'll be very helpful, and I want to respect that person's privacy and give them space. Is that the right approach?

LEANNE: It can be, if you are comfortable enough to ask the question, because again, the grieving process isn't about us as the neighbour or the friend or the work colleague or the family member. It's about the person who has lost somebody, and they may be responding to their grief so differently to how we do. It's about asking the question, what do they need? How can we be of support?

RITA: So, the work that you do in end of life, can you talk a little bit about that and what you think might constitute a *good* death? Is there such a thing?

LEANNE: Can there be joy in death? Can there be joy at end of life? I'm going to say absolutely because I witness it every day, whether it's the work in the hospice or the work that I do with the Motor Neuron Association as an end-of-life consultant. I do a lot of family mediation and I see the difference. I'm so blessed in my work that the families that I work with teach me so much about living and understanding our timeline here on Earth.

The ones that openly talk about it are not as fearful of having the conversation, they're comfortable knowing that they're going to be okay. It's actually the ones that they're leaving behind that they are most concerned about. So anticipatory grief is obviously when you know that someone is going to die, they've got a terminal illness. And again, there is no awareness or education. So, a lot of people don't even recognize that they are actually grieving. And of course, I see it a lot with illnesses like motor neurons, where the wife or the partner becomes the fulltime carer. So, there's things like compassionate fatigue, carer fatigue. The roles have changed very quickly in the relationship. Those micro losses, even in the anticipatory grief, they're grieving the loss of the intimacy in their relationship. They're grieving the loss of going for a walk with their partner on a Sunday or taking their dog for a walk together. They're grieving the loss of the handyman that can climb the ladder and change the light bulb. But in the business of caring for their loved one with a terminal illness, they don't really give themselves permission to explore their own emotional journey because the focus is a hundred per cent on the patient. But again, through education, every time I

work with families, they are so grateful that I actually allowed them that space to just acknowledge their own journey. Whether it's compassionate fatigue, carer fatigue, talking about anticipatory grief or their own losses through the journey of that terminal illness, the more that they explore and express and understand their grief pre-death, it really does prepare them and develop their own awareness, their own personal understanding.

Now it's not a conversation we need to have all the time, but I see it in death cafes. I see it in compassionate community forums and workshops when we've held them. They've developed their awareness. They have a deeper understanding; they acknowledge the importance of these conversations. They feel more comfortable in it now. So therefore, they are more prepared when it's necessary to support someone in our community.

But this is what I love about my work is [that] the first second of life is also the first second of death. We don't know how long we have here. This is what I share with my clients all the time, I do challenge them. I challenge them greatly to have a conversation around death. At first, do they want to step into that conversation? Not necessarily, but every time [they do] they are forever grateful for the journey that I took them on in understanding their own awareness of their own mortality, their life story, their values, their beliefs, their love, that they've shared the stories and the memories that they have of their life, the balance of the joys and sorrows. I share it all the time. Both of them are just as important [as each other]. They have an equal space within time. I find that no one has time for these conversations. No one has time for grief. That's why I love my work, because I have so much time for it because I see the importance of it every day.

RITA: So, is there a finite time for grieving? Can you get over the loss of whatever it is, especially the loss of a loved one of course, do you ever recover?

LEANNE: No, I don't believe so. What I have observed in my work is everyone is very different and there's no right or wrong and everyone brings something quite unique to their own experience through loss. What I have observed is grief becomes a part of who we are and it stays with us forever. It's how we manage it in regard to our own self-awareness, and I talk about self-awareness a lot because I do believe that that is the most important element to understanding who we are with grief.

I'll share a story. I worked with a wonderful lady. I got to know her through a very interesting part of her grief [journey] actually. She lost her daughter two years earlier to a brain tumour. She thought she was coping quite well, very intelligent lady, very much aware of her own emotional wellbeing, had the self-care strategies to take care of herself. Two years later, she was walking down the aisle of Coles and she had an emotional outburst, and it was when she saw the rice bubbles and the rice bubbles were her daughter's favourite cereal. Now, why was it that for the two years earlier, she had not had that same emotional response walking down the cereal aisle as she would have every week? That's what we call our micro losses or our secondary losses. We have thousands and thousands and thousands of those associations that are deep within our subconscious. It is about timing. There was a timing on that day [where] the body has a response to our emotions. That's why a lot of the work that I do is body-based therapies. But that was a real demonstration of where, you think you're coping exceptionally well, but the memories of, whether someone was in your life for 60

years or 21 years or five years, we have that association of all the little things that we did with them daily.

I see it with beautiful community members that I work with at the hospice that may have recently lost their husband. They lived with them for 60 years. There are many, many, many micro losses there that they need to develop awareness of to understand why each day carries a different emotion or a different experience. And yet they don't understand their grief because they don't give themselves permission to explore it, to express it, to understand it. Once they do, they're like, oh, that's why on a Friday afternoon and I sit on the veranda outside, I'm just a mess, because every Friday afternoon, that's where we sat for our wine and cheese and biscuits. So, self-awareness is the key.

RITA: Is it important, do you think, for public institutions to play a role in helping people acknowledge that death and grief and loss is part and parcel of living? I mean we pay taxes, should local governments and federal governments look at that and say, well, this is something that we need to spend money on?

LEANNE: Yes, and I do know some government organizations or local shires that do invest. And the difference that it's making is quite incredible. I think that it actually shows the people of our community, from those levels down, why it's so important, and certainly caring for our elderly community is everyone's responsibility. It's not just the health sector or the government in regard to all the different areas of which the elderly can seek support. Let's take it back to grassroots. Let's take it back to a really humane response to everyday people that walk through our community.

One of my areas that I want to do a lot of work around is compassionate workplaces. Do workplaces have a grieving policy? Generally, 90 per cent of businesses would never consider it. Yet, if a work colleague loses a partner, they have a couple of days off work and that's it. Everyone in their office will avoid the conversation at all costs and everyone's just expected to get on per normal. But if we can develop a compassionate workplace where they see the importance of grief, if someone has lost a partner in that workplace, I can guarantee you that it'll have an impact, an emotional impact, and probably reignite someone else's grief within them. Therefore, everybody in that workplace needs support, but we still live in a culture where we avoid it at all costs and everyone gets on with their work, hides behind their computer and goes home and probably has a very emotional response at home. Yet it's never spoken about, but every time that I bring a group of people together and have the conversation, everyone recognises that everyone had a response to it, and everyone needed that opportunity to debrief, explore it and understand it together.

RITA: So, speaking about togetherness with the last couple of years, with a pandemic, with lots of people feeling very, very unstable; do you think that loss and grief has played an important part in people's everyday experience?

LEANNE: I think that's probably one of the positives to come out of the pandemic is that everyone has acknowledged loss and grief to a greater extent than we ever have before. We've really considered our own mortality. We've considered our community and how we can support our community. I know when the pandemic very first started, there were some

incredible stories within our community on how we were keeping an eye on each other, how we were aware of what was going on in our street and what we could do to support one another.

One of the other things that we saw through the pandemic was loneliness. Research has shown that loneliness kills more people than cigarettes. And so, through the hospice, we developed a grief line, a 1800 line. And the majority of people that called that line were just elderly [people] at home wanting to talk to somebody. So again, when we understand grief, a grief line, a 1800 line for somebody to call, isn't necessarily the grief of losing someone to death and dying. In their grief, in their sorrow, can be many losses. A loss of going out to play bingo in their community, which is their one day a week where they go out and connect with other people.

RITA: Another aspect of COVID was that when people lost families who were somewhere else and weren't able to go and grieve, weren't able to carry through those rituals, especially with diverse communities that come from all over the world – there was suddenly a media phenomenon of a 'Zoom funeral'. What kind of impact do you think that that will have when we look back in 20 years' time when people are researching all the different things that happened? Do you think that the ability to be able to connect technologically eased that feeling of loss or did it contribute in some ways in a negative aspect?

LEANNE: I have seen the power of connection online through what we call Zoom. I have seen that through my own work and I was someone that always said I would never take my work online, that human connection is really important in this work, but I've also come to realise you can develop that human connection online. And that's really beautiful, but obviously that's in my professional role. But I've seen some incredible things happen throughout the pandemic where the importance of rituals have come together, where they have live streamed it at a drive-in theatre and everyone's in their cars. So, there's lots of special things that have still contributed to people coming together. It has been difficult, however, to see many [people] that are dying in hospital and haven't been able to have their loved ones by their side. I think that is very, very important.

RITA: Have you experienced a loss that you feel has really impacted everything else that happened in your life afterwards?

LEANNE: There's many. And again, it really demonstrates the grief response to loss. So, the loss of my mum ended up being such an incredible story for many other reasons, through demonstrating to my family the importance of love and respect. But I also have to say that the grieving response [I had] to empty nesting when my children left home was something I never expected because I was very proud of how we'd raised our children. They were ready to go off into the world. So, I never thought that empty nesting or that loss of my role of taking care of the kids and them being at home would ever impact me, but it hit me hard. And so, you know, that was something for me to sit and acknowledge and respect and honour at that time. But also, the grief of a loss of a friendship that couldn't be repaired. There are so many.

RITA: Do you think we think enough about and we prepare our families enough for that inevitable loss?

LEANNE: I don't think we talk about it at all in regard to loss. Everyone's very different in their grieving process and everyone manages emotions very differently. Some people have a natural strong constitution to resilience. I've seen that there's no hierarchy to grief and what I mean by that is someone's response to the loss of a loved one to murder, and then someone's response to the loss of their pet, or an auntie that they never met, can be very, very different. That all comes down to their resilience, their community, their culture, their personality, their character, their coping skills, many, many, many factors. So that's why there's no hierarchy in grief. It all needs to be respected.

We are so uncomfortable with emotions that [we think], quickly get over it. We've got to get back on with our work. We've got class to finish, as an example. But I want to challenge people that, if we allowed a student, a work colleague or a family member to just sit and openly express their emotions, whether that's through crying – don't stop it, try and fix it or resolve it. Let's relearn the importance of just sitting with someone. So can you imagine in a classroom, if a child has come in and they're grieving the loss of their auntie, and they just started crying, rather than taking them out of the room or quickly trying to stop them and soothe them, if we were to have all of the students just come and sit in silence and sit around and respect and honour that person – the difference that it would make.

I have accommodation at my Centre, and I have clients that come down and stay for the weekend because sometime a one-hour session is just not enough. If you've just lost your husband to suicide, and there's many complexities around that, you need a good couple of days. I've had people in my clinic in the foetal position, screaming. Allowing time for that and to observe that, the difference that that makes of being very comfortable with all emotion is a ritual in itself. Is the process of grief itself expression, where we now live in a community where expression is avoided at all costs, because we don't want to be seen as needing help because we're overly expressing? But some people get a great relief from that.

RITA: Do you think that the modern loss of faith perhaps has a role to play in how uncomfortable we feel with loss?

LEANNE: Yeah, I do. And whether that's a faith on a religious level or even a faith in ourselves, because I think both are missing. Whatever your needs are, whether it's a faith in ourselves or a faith in your religion. Again, we don't have culture, we don't have our values and beliefs and that's something else is that I ask a lot of people, what their values are, and they don't know.

RITA: Is it possible to have those conversations with people at the end of life?

LEANNE: I do. Can other people do it? I'd like to hope so, I'd like to think that we can develop a compassionate community where we're very comfortable to have those conversations, because when we are connected to our own values, it's very easy to support others in theirs. So, I'm going to say that a compassionate community is a community that understands values.

RITA: One of the things that is often a default position for people is that when they get referred to palliative care, they're very negative about that. They don't understand what it is, and they really kind of think it's the medical community giving up on them, putting them in the sin bin, in the waiting room and that nothing else can be done. Is that your understanding of palliative care?

LEANNE: I think palliative care are working very, very well at the moment to change that perception. And certainly, working through the hospice and through palliative care in the Southwest, I have seen that our community has a better understanding of the services and also their options to be able to manage their terminal illness at home and not necessarily go into that medical setting, which can make a huge difference to their comfort and their surroundings in their illness or at end of life. So, I'm very passionate about that work in our community as well. But I think there is a shift in the understanding of what palliative care is. We are starting to see a shift in the understanding of end-of-life choices. A lot more conversations [are] necessary. But we asked through certain programs that have been developed in our community through programs that allow volunteers to go and support people in their home. Yeah, so there is a lot of incredible work happening in our community. One of the greatest ones that we observe is going back to knowing how to ask for help.

RITA: Last year, the WA government was only the second [state] to pass a voluntary assisted dying bill. How important do you think it was, on that public level, for government to recognise that this is a debate and that there is a choice and that that choice should be given, within of course, parameters?

LEANNE: I think it encourages the conversation, whether that's within families, within the greater community or within large organisations, and then up to government, it encourages the conversation. Everyone knows somebody that deserves that right, rather than to live in pain, in suffering and a long, drawn-out illness, where they're no longer capable and they feel that they are a burden to their family or even to the health system. It's unfair that someone at that stage shouldn't have a choice. I see it all the time in my work, and of course, very much so in the motor neuron [area], which is such a cruel, cruel disease. I work with many families that have made that choice for VAD. And look, I've seen varied responses to it, but ultimately it is honouring someone's choices that are in a very horrible situation.

RITA: I was going to ask you about whether you ever contemplate your own end of life and what that might look like, and what you would want, and whether you are able to openly share that with those who are closest to you?

LEANNE: I've absolutely documented all of my end of life wishes, but more importantly, the rituals and what my wishes are around my funeral planning. I know that that day will be a great demonstration to my community and the people that attend. If that day makes a difference to understanding end of life and grief, then my work is done.

I think when my children were younger, they thought what I did was weird. Didn't want to know about it, just thought it was weird what Mum does, but now as adults, they're quite intrigued, they have the conversation. They've attended some of my work. They've seen me

in my community sharing the importance of a compassionate community. They're out in the world themselves now creating their own life [where] they're starting to see family, work colleagues and communities respond to grief. So, they're starting to develop their own values around it, which I believe is probably one of the best things that I can give them because they value life. They're grateful for their life. They're grateful for the people that they meet and come into their life as well. So yeah, my funeral planning is going to be easier on them, but it's also going to be a demonstration of my values.

Death can inspire us. Some of the best music, some of the best art, some of the best literature, poems, and love stories actually come from death. Death inspires us to live better lives. It certainly does for me and my work. As much as it's an honour to support families at end of life. Death inspires us to help each other. Death inspires us to be present, to be in the moment. Life gives us two great gifts, love and death. We can't have one without the other. The only reason we grieve is because we loved.

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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