

Elizabeth Eckerman

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Elizabeth was interviewed 30 April and 2 May 2019 at Barwon Health's McKellar Centre. There was more that Liz wanted to say, but unfortunately her deteriorating concentration and energy meant that it was not possible to continue as hoped and planned.

> Interview & editing by Russell Armstrong Transcribed by Lorelle Abbott Barwon Health Palliative Care

Elizabeth Eckerman: some life reflections

RA: Liz, you earlier shared with me that you've been thinking a lot about your illness, and what it means for you, for your family, and for other important people in your life.

I guess quite dramatic changes have happened in my life, particularly over the last year and a half. My life has changed quite dramatically, particularly in relation to the impact on family and the impact on a variety of different people, and obviously it's had a huge impact on my life generally, and I guess there is no other word to describe it other than absolutely traumatic.

But at the same time it's also been interesting. It hasn't been a sad time; it's been an interesting time. It's been a time of enormous reflection, and an opportunity to think about how other people might have been impacted by this process as well. A lot of people have been very, very important in my process of coming to terms with this insecurity, and coming to terms with all kinds of issues that you wouldn't expect to have to deal with.

And yet it has been an easy role in a way, a fairly straightforward role to play. I hadn't expected to have to play this role, but it is also manageable and it is also something that I can hopefully approach in a very positive kind of way. And the way I think about that is that it is not sad. I don't feel sad. I'm not feeling sad. I am feeling like I want to participate in the process, and I feel like I want to be part of it, and that I would very much like to be part of life for the sake of everyone who is around me. It probably sounds a little bit trite in a way, but it helps to... what is the word? I am trying to think of a word that is...

RA: I'm wondering if you are saying something about acknowledging that this is a terminal illness and that you are dying, and that rather than avoiding that you are choosing to confront it and deal with it as best you can? Is that sort of it?

Yes, thanks for that; that helps a lot. In a way I am almost, I wouldn't say enjoying it, but I would say that I am participating in it, that I am embracing it with energy and with positivity, and thinking about it in terms of how my family particularly might be part of that process with me, and be really part of it. It's not only my own personal circumstances, but also the circumstances of the people whom I have been involved with in the last however many years. How many years has it been? It feels like hundreds of years; it feels like a lifetime of energy, a lifetime of experience that is very positive.

I think that is one of the very positive aspects of it that I feel at the moment: I feel a love of humanity that I probably haven't felt as strongly before. It's in relation to being able to think about loving people, being able to approach people, feeling part of humanity generally, wanting to be part of humanity, wanting to be part of everything that is going on. And certainly I continue to do that, and I will



continue to be part of that continuing humanity, a very centralised part of humanity. Sometimes it gets a bit confusing trying to express myself.

RA: I've almost felt like I've heard you say there is something almost empowering about being honest about what is happening with you and dealing with it.

Yes, it's empowering; it's very empowering. I think an enormous amount about my family and how they have participated in it with me and what part they've played in it. I think of how other people have shared in my human suffering and my trying to grapple with reality. I feel very deeply connected to other human beings, which will never go away, but which is also quite humiliating as well. It slows me down sometimes. And it is a good thing sometimes to slow down isn't it; you can't always be travelling at a thousand kilometres an hour, trying to leap along the freeway, not when you really are trying to deal with deep aspects of humanity that needs attention. I think I feel a need to pay attention; I really feel that life needs attention at the moment, more than we have needed it throughout history. It might sound a bit trite, but I really do feel like we need to pay attention to life.

RA: If what you are saying is that humanity is poised at a very critical and delicate point in its history I won't argue with you on that!

It is very sad, but I wonder if there is a kind of goodness that hasn't yet been practised or hasn't yet been experienced, but which might happen in the future. It's a little bit frustrating from the point of view that I feel like there are some little things that are on the verge of developing, and I'm hoping that they will emerge into something that is very, very positive in the future. We just have to be a little bit patient, but sometimes I feel like I don't have that time. A little bit more time would have been nice, would have been good, but never mind.

RA: When you say that about more goodness to come but not enough time, I trust and hope that Martin Luther King was right when he said that the arc of history bends slowly, but it bends inevitably towards justice.

It does. He is my hero. You are right; it has been a continuing kind of healing process for the whole of human history, and, Martin Luther King was such a positive part of that. Imagine if we'd lost that; Imagine if we'd lost even one cent of that deep and intense expression humanity, what a loss that would have been.

RA: And imagine if he hadn't been cut down when he was.

Yes, exactly. There have been some fantastic, positive aspect of humanity, but there have been some really pretty nasty processes as well, and hopefully we will come to terms with that. I do worry enormously about the future in terms of what's happening, seeing some people developing into the types of human beings that we don't want to happen. This is an issue I would love to explore more and I will explore this more if I have a few moments throughout the day when I can reflect on some of those kinds of things.



There have been some lovely experiences; I cannot believe the love that I have been delivered from friends and whoever the past three, four or five years. It is just unbelievable, absolutely unbelievable, incredible!

RA: It has been the blessing alongside the curse of the cancer?

Incredible. It stuns me. I can't even start to register the level of love that people can feel towards another human being, and the capacity of human beings to feel love towards each other. It has just been incredible. And I'm sorry if it all sounds a bit trite today, but it is certainly something that I will continue to process if I've got a bit of time.

RA: I don't think it sounds at all trite, Liz. I think it sounds like what I would say is the truth of the situation - that if you're honest about acknowledging life and death and the connection between the two of them, and reflect upon that, then there's the opportunity to learn about life and to appreciate it more richly, which I think is what I'm hearing you say.

I'm just hoping that there will be a little bit of opportunity for more of that sort of reflection; I don't expect too much, but I am expecting some opportunity to be able to reflect on that. And I'm sorry, it *does* sound a bit weird, and it is probably nothing like what I would have written six months ago or even a little while ago, but it's just the capacity for human beings to be able to express that sort of love and care. And people have come out of the woodwork, you don't even know. Isn't it incredible? Why do people come out of the woodwork, come out and talk to you about things that are just so enlightening? And you think, "Goodness me, how on earth do people know about these things? How on earth have people grasped these incredible understandings and comprehensions about your own life? It is just fantastic.

Every day I go past Breamlea, and I don't think there is a single day that there aren't at least half a dozen people who come past and say what they need to say. It is incredible isn't it? It doesn't matter what they are talking about, they just need to say it. It is lovely from that point of view. I just love it, and some of the things that people say are just so beautiful. I am just in tears a lot of the time, but in a really good way. They have offered some lovely, lovely responses, hundreds and hundreds of them. I am just very, very grateful that people have done this, and not only for me, but have done this for other people as well, done wonderful things for other people as well. So yes, they have just been incredible. I just can't believe it.

I just love conversation, I love knowing, I love being; I don't know how else to put it. It's such an energy, such a very, very positive energy you couldn't describe in any other way.

RA: So there's been a life and energy to you when you're talking with people you've felt connected with?



Yes, it's been fantastic. I can't imagine what life would be like without some of that. There are people who have entered my life in such a profound way, with such a positive energy.

I love nature; without nature life wouldn't be worth living. I love just watching butterflies, watching animals, watching things happen. Life becomes beautiful and surprising and fantastic.

But the biggest thing is the humanity, meeting some of the most amazing human beings in the world.

I would like to write down some of the things to thank people for what they have said, and in relation to their positive contribution to humanity as well.

RA: Part of the beauty of this process is that it is sort of an opportunity for you to collectively thank people.

Yes, thank you; that is a really positive aspect of what we're doing. They have been fantastic. I don't know, it is just overwhelming. Goodness me, imagine if I'd missed out on it; wouldn't that have been terrible. Imagine if I'd missed the moment, if I'd missed the opportunity to say what has to be said and to do what has to be done. It would have been terrible if that had been missed, but it hasn't, so from that point of view I'm not feeling sad at all. How old am I know? I think I'm sixty nine, something like that, and that's alright, isn't it? I reckon that's alright; for me that's fine.

RA: A little earlier you said that your experience has been positive but it has also been humiliating, which I guessed is a reference to the challenge of finding yourself as the receiver of care after decades of such a distinguished professional career?

Yes, and how grateful we must all be for the fact that at the end of life that becomes the reality, so it is humiliating, not in a negative way, but humiliating in the sense of life slowing you down and presenting you with all kinds of things.

RA: I was wondering whether perhaps 'humbling' is a word that captures what you are saying without the possibly harsh overtone that the word 'humiliating' might have.

Yes, perhaps it has more of that sense, and that has a more positive sort of an effect. But humiliating is also important too. If we don't think about things like that and if we don't accept humiliations I think we can lose our humanity. In a way it's... I don't know quite how I would describe it?

RA: Is there something grounding about a little bit of humiliation?

Yes, a little bit of humiliation. It is not as if I am trying to put myself down or anything, it's just saying, we need a little bit of solidness, a little bit of solidity to ground ourselves. Solidity is really important I think at sad times. I quite like it. It sounds a bit weird doesn't it? I quite like the solidity of really experiencing



something in a worldly sense, not just in a kind of cloudy, fluffy sense. I am not fluffy; I'm not a fluffy girl.

RA: Am I getting ahead of things to wonder whether you are almost saying that this is a humiliation that still leaves your sense of dignity intact and maybe even leaves your sense of dignity enhanced?

Yes, hopefully. Hopefully it means the world doesn't have to accept some of the hardness of reality. We need to remember, I need to remember, to feel that I am in still in touch with humanity and still in touch with the proper existence. This is starting to sound weird. I mean getting in touch with the gentleness of reality, a real existence. I think my family is a bit tough, but maybe not as strong. I feel like there is a strength that I still need to experience and to push for in my existence, which is about not letting anything drop and just helping my family be strong.

RA: As I am hearing you speak I think of the word "grace". It sounds to me like you're talking about responding to your illness and the humiliations that come with it with a sense of grace, and because you're responding with grace you're ultimately experiencing it as being relatively gentle to use your word, and you're becoming more in touch with that sense of humanity. I meet other patients who respond to the humiliations and the disease with resentment and they fight it and it's an entirely different story. Does that make sense at all?

Yes, yes, I think you are right. I think there is a sense in which I am going to enter this in the gentlest way, in humility and without embarrassment.

RA: With grace and dignity.

Yes, that's right.

RA: The other image that came to mind is that in the face of the challenges of a disease such as yours and the suffering, some people can respond to that with a rigidity that means that there's no room to bend and it can break them, whereas, perhaps you are talking about a strength which is also malleable, it's able to change in response to the challenge and so is not broken by it, whereas, when you resist, it's almost like you become brittle and you can be broken.

You see when I think about it now I could have become brittle and brisk. I was thinking about this just yesterday. It was something that I had to come to terms with as well. It wasn't as if it was easy to me to just let go of my career and what I've worked for and earned and leave them to others. But it's alright with me now; it doesn't worry me anymore.



RA: There is no point dwelling on it and developing a sense of cosmic injustice.

No; what's the point? It wouldn't make any sense would it?

RA: Liz, what have you learnt about life that you want to pass on to others?

What have I learnt? The most important thing that I have learnt about life is that the material stuff is irrelevant in a way, maybe not irrelevant, but it doesn't matter. None of the money stuff matters anymore; money is irrelevant totally. And I've learnt that my kids and family are so important to me.

