



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

Submission Number: 364

Date Authorised for Publication: 19/4/18

Secretary,
Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT,
GPO Box 1020,
CANBERRA ACT 2601.

My name is Amanda. I am a palliative care specialist working in the community. I have worked in Northern Territory of Australia and had the privilege of looking after a number of Aboriginal Australians. I could have been a heart specialist or a lung specialist, but I chose to work with those with a life limiting illness, palliative care.

I spend my workdays driving from home to home talking with people about their illness, what it means, what is to come. I see the fear in their eyes start to fade as they understand what is in front of them. I discuss symptoms and medication with them and their loved ones. I also work with an amazing team of nurses and allied health who spend everyday going the extra mile for patients and families. We have the hospice which is a beautiful place with a garden and single rooms, quilts on the bed made by volunteers. Everyday families come in, many anxious about what a hospice looks like, only to find humour, warmth and colour.

Then I see in the media people saying that palliative care does not always work, and we need to have legalised suicide carried out by doctors. That simply does not make sense to me. Palliative care is not a pill. It is not a medicine, a treatment or an intervention. It is an approach. It is someone asking you what life is like at the moment. What is important to you, how you want your life to be from now until the end. It is about choices, dignity and care.

Palliative care teams often have dietitians who talk to you about food and appetite, a physiotherapist who helps with mobility, and OTs who work on your function. We have counsellors to help with emotional stress and spiritual care, social workers to give advice about benefits, funerals and planning for the future financially. Each part of someone's life is seen as important and includes their families, friends, pets and even neighbours. I was recently interviewed by a reporter. He and the cameraman spent 5 hours with me seeing 3 different patients at home. When he left the cameraman said to me "who wouldn't want all this?"

You will hear anecdotes of relatives who died badly and I acknowledge how terrible this must be, and it upsets me because it doesn't need to be that way. Medicine does not always know when to change focus and allow a natural death. It does not always know how to reassure, normalise death and support families.

This is one of the reasons I was attracted to palliative medicine. Our philosophy is neither to hasten nor to postpone death. The fact is that those who work more closely with people at the end of their lives are more opposed to assisted suicide.

But today I want you to hear not my voice, but the voices of those I help look after. I want to tell you the story of Bob. He was referred to me by the lung specialist. He does not have cancer but scarred lungs which are getting worse. By the time he opens the door to me he is quite blue. His lovely wife

Anna is also there and they look apprehensive about seeing me. I spend a bit of time getting to know Bob. He loves fishing and his grandchildren. As the conversation goes on I find out that he takes an hour to get showered and dressed because of his breathing. I discuss ways we may be able to help that and he is pleased to hear about the options. He then asks me about the future. He gets anxious when he cannot breathe. I see where he is going with this conversation. I say "Bob we will not let you gasp to death. This is what we will do." His wife looks shocked, both at what I have said but mostly at missing what had been weighing on Bob's mind. I ring them a week later. I talked with Anna who told me she understands so much more now about how to help Bob. I spoke with Bob who sounded bright. Thanks he said I feel so much better. It was a 55 minute conversation with Bob and Anna and it completely changed the way they view the future, empowered them with knowledge and took away their fear. That is the power of palliative care.

It is about conversation, communication, knowledge and power. It is about acknowledging that death is normal. Not only that, it is transformational and only understood by those going through it. Well people speak as if they know, but they do not.

A 94 year old lady [REDACTED] reminded me of this. She asked to see the palliative care doctor. She was in a room in a nursing home with her daughter. She wanted someone to stop all her heart medication as she was sick of taking tablets. She said to me "in any other century in history I would be dead. Please let me go." Her daughter nodded and they had obviously talked about this. I said that was OK with me and when did she want me to stop the medication. Tomorrow? Sure I said. She looked at me with a beautiful smile, shut her eyes and said thanks multiple times. This is what palliative care is about: listening, giving choices, learning and allowing nature to take its course. This was withdrawal of treatment which is totally different from assisted suicide. She did not die of a lethal injection, she died of her heart illness 3 days later in her own bed surrounded by family.

There are hundreds and thousands of people like [REDACTED] in our communities. They want to be cared for, heard, valued.

People who say that palliative care does not always work are doing great harm, because they are raising fears for those people, not reducing them. The evidence shows that people who engage in palliative care early not only live better, they live longer. That is the truth that needs to be told.

Fear of the unknown is what people grapple with when they are told they have a limited time.

From the minute you are diagnosed with an illness that is ultimately going to take your life a transformation begins. Well people do not understand this. They base their opinions on what they think they would feel and want. But illness changes you. It becomes a re-focussing on others and other things. People worry for their spouses, children, friends, workplaces and pets. It might be their body, but the choices they make are intimately tied up with others. This constant voice of "its my body, my choice" is so false, and elevates autonomy over and above everyone and everything.

Listen to the young man who has not told his wife how much pain he is in so she will not worry. We are helping him with that. Like the 50 year old woman who wanted to be there for her son as he did a big event he had been training for a year. We encouraged her to make a banner for the family to hold at the finish line. Like the 75 year old husband who was desperate to see his new house built so his wife did not have to worry after he had died. He sat in the window of that new house with his

son, had a glass of wine and died the next day. I could go on and on and on - these are only recent stories.

These people I have had the privilege to look after are the reason I am here today. To give them a voice as they have gone. I have heard them. So I ask Canberra: what kind of society do you want to be?

Do you want to be a place that endorses fear, that says "You're right to be scared, it's going to be awful"? Do you want a place that has legalised killing by the medical profession?

Or do we want to reassure all the Bob's and [REDACTED] that they are safe, and loved and valued. That they are not a burden, that their symptoms will be managed, and they can put things right before they die.

For every story that you hear of bad deaths, think of Canberra as a place where everyone strives together to make this better.

Thank you.

Dr Amanda Landers
Palliative Care Specialist