

## Transcript

Gillian Mears address to Dying with Dignity NSW Parliamentary Forum

19 November 2012

I'd like to begin by paying my deepest respect to the Eora People on whose land we are sitting and I am going to take the chance to also whizz a salute to Phillip Adams, who I have more or less been stalking since I was a child. Keen high school student, every prize night I would be getting my new unspeakable Adams, little knowing that we would be meeting, at last, with a Forum to do with death but thinking of our respective predilections for writing about death, it is kind of appropriate.

Not a day goes by that I don't wish that I were dead. It would be so much easier than living now in a body that, after seventeen years, has simply had enough of advanced MS. Every morning I wake up at 3am and there is absolutely no point trying to sleep in because my once lovely horse riders' legs have turned into crowbars and they tangle in the night. And I sort of lie there and I listen to the September/October birds and if I'm lucky there might be a Tawny Frogmouth as well, calling, and then I'm faced with the task of trying to untangle the legs and I swear terribly, I swear and I howl and I just think I'm like the Little Mermaid in terrible reverse. It's as if my knees are sticking together and my legs are turning into a tail and it is not a tail I really want to be living all that much anymore.

And I have to be very stern not to think of my blithe years when, MS and all, I had converted an old F100 ambulance into a campervan and I had the freedom of travelling and of being very alone, alone and wild, really and in those days I thought of myself as being like Kipling's *The Cat Who Walked By Himself* and I could walk by myself in the wild woods, waving, if not my wild tail then my wild walking stick.

So I look at the clock, calculating how many hours I've got until my first carer of the day arrives because solitude for a writer of my ilk has always been so essential and I'm always panicking that I'm not going to have enough time alone and when I hear the noisy mynah birds begin to attack my cat I know I've got about forty minutes before the first carer of the day arrives and one of the marvellous things she first does is give my legs a massage and she might well say "these legs feel like they're made of stone" and inside I'm just wailing: "I wish I were dead, I wish I were dead, I wish I were dead, dead, dead." Like the Channel-billed Cuckoo, it's this wail.

Some mornings I am truly haunted by the ways outlined in the Philip Nitschke book like how to put your head in a plastic bag so it will most successfully suffocate you or the exact angle to put the tip of the rifle in the roof of my mouth or Mexican Nembutal that may or may not work. I find that such a distressing book, I really do find it distressing, especially in the light of my grandfather; his death was really a bad death, also he was a sufferer of MS and I'm 48, he was dead at 50 and before he died they amputated both his legs at the thigh because it's kind of easier to look after adult incontinence if you don't have legs and then they put him on the top floor of a hospital for incurables and he went blind and then he died and I've got an advanced directive in my will. Everything in me is aiming to guard against such an unenviable fate.

I often say, look, if I were a cup of tea and you were to sip me your lips would curl because I'm such a dark and bitter brew now. I didn't ever imagine this would be my life. Had somebody told me a few years ago that I would be part of today's forum I just would have scoffed with utmost incredulity.

Now comes a confession hitherto untold to anyone at all - I can't believe I'm going to tell you this but I must. Well, five years ago I was in the company of a man very interested in euthanasia. His mother, his

glamorous mother, who had been a stand-in for Greta Garbo; she was Hollywood-sort-of-glamour and she had been a member of the original Hemlock Society, he was very interested in euthanasia as was I from a theoretical point of view and so we tuned into the *Insight* documentary on voluntary euthanasia which I'm sure quite a few of you in the audience might have also watched and my friend was booing and hissing Christopher Pyne, the then Federal Minister for Ageing, and I fell quiet because I found myself, unbelievably, having the opposite reaction so much so that I found myself the very next day penning a congratulatory note to that very politician! How could this be? As anyone who knows my writing or me would realise full well, I've not ever been of the same political persuasion as Christopher Pyne. I'm no friend of the fundamental Religious Right. In fact, the same had chucked one of my books off the HSC syllabus not so long ago and yet I was compelled to write to him.

In my memory, my letter even said something along the lines of "he has shown such intestinal fortitude in the face of the angry death-desiring mob that he might even be Prime Minister one day." I know! Kind of unbelievable. As he never replied and I kept no copy of this strange outpouring I wish I could pretend that it had never been written but somewhere in the Pyne archives, there it will be.

In a sense, I shared Pyne's hubris about suffering because even though I'd had MS for twelve years at that point I was more or less very cavalier with it and I had this horror at all the people in the audience, their zealotry to mark themselves "not for resuscitation" - it was just showing no imagination about suffering and I was the same with fellow writer and MS sufferer George Papalinus when he wrote an essay that was published in *Heat* saying that he may well choke to death on his own saliva. I just thought "Oh come on, George, just put a bit of will power into the disease and that won't be your fate".

However, one point I would still agree with Mr Pyne on is that when the voluntary euthanasia bill is legalised- for I can't believe that in a humane, democratic society this won't happen and hopefully it will happen soon but I hope that it will be always with the firmest of safeguards otherwise - I did, when I wrote the letter to Mr Pyne I had this image of kind of a factory of death like, you know, old relatives just being shunted off to be put down for their life and I cherish old people, as anyone who reads my writing knows, they're part of the celebration of my life and one of my favourite books was Elizabeth Jolley's classic *Mr Scobie's Riddle*, and if I'm remembering correctly there was a niece and nephew in that book who would have thought nothing of just putting Mr Scobie down to get their hands on his house.

Now I must ask the cat lovers in the audience for some patience as I turn to a few dog stories pertinent to today's Forum. Even though I was always a girl with a cat, I grew up with three dog-loving sisters and the next story is about my mother's dogs; Chief and Zula, a pair of Staffie Bull Terriers that were also affectionately known as "The Rhinos" because they were so heavily plated in gleaming, black muscle.

They were a pair of dogs who had become so human that they had even learnt how to pull their lips up and back into this human smile; they really were a very wonderful pair of dogs and just to give you an idea of my true affection for them; when I came out of open-heart surgery, the first thing I said to my father in the intensive care unit was, he was kind of sneaking in, sneaking in, I said "you look just like Chief and Zula creeping in".

It's my final memory of that fine pair of dogs that informs my belief that there must be nothing arbitrary about the way voluntary euthanasia legislation is eventually enacted because well, the Staffie-years passed and gradually their snouts whitened and all the indignities of old-age came upon them and they lost continence, they lost the ability to move and it was dad who took the very draconian step of whizzing first Chief and then Zula off to the vet. I didn't go but I did help bury those dogs and I will never

forget the look on those dearly beloved snouts because their lips were pulled back in this grimace of agony, basically, because they had been so summarily executed at a vet's where, I mean, not even a well dog loves to go to a vet and I just thought it was that expression on those dogs' faces as much as anything else that had me writing that letter to Christopher Pyne.

So, fast track to a dog I met far later, and this was Bruce Pascoe, my first publisher's dog, Reg, kind of a half-cross black kelpie and Reg, he was a dog who knew all about irony. He had this way of, he could roll his eye up to catch your eye to see that you kind of got the amusing joke that was happening but nothing ironic about a terrible cancer in the right hind quarters. Eventually Reg was in extraordinary pain, so much so that he would no longer have a conversation with you, he no longer wanted to catch your eye and Bruce called the vet but the vet came to Reg's house and so Reg died without even knowing, he wasn't surrounded by terrible fear, his head was in Bruce's lap and it was a really benign and beautiful death and I often think of that.

Thank you for your patience in listening to a pair of dog stories but I think it is harder to discuss as openly the death of people.

I'll only touch briefly on the death of my mother, but only 54, in a couple of months cancer withered her away like a little leaf before the final structure of the disease turned her body into the size of a 44-gallon drum and just the terrible terribleness of this; my lovely mother and her struggle towards death and the long death rattle with all the suffering and I know what her decision would have been had there been voluntary euthanasia legislation in place, I wish there had been.

I don't know if others in the room might feel like this, but the older I grow, the more I want the last mouthful of every meal I taste to be a delectable one. I'm really serious about that, I want the last sliver of my Sunday pancake to be the best sliver, the best, crispiest morsel of that pancake and it's the same when I think of my life. I want the last mouth of my life to be a delectable mouthful and in the event that unbearable indignities arrive before the wise legislation arrives then I'll have no choice but to take my end into my own hands. And although my little sister waxes lyrical as any Farley Mowat short story about the ease of dying in the snow, were she to assist in building me my last snow cubby or even trucking me up to Kosciusko, she'd be charged with my murder.

And in quasi-romantic fashion, back in my camping years, I used to imagine "look, I'll just take my old ambo out into the Malley and I'll just end my days semi-romantically out there" but having seen a goanna disembowel a half-alive possum, I think it would be a scenario too grim even for Philip Nitschke's book and coming up now anyway were two years since I've relinquished my license so now what? Well, not being a wheelchair woman, sort of, off-the-Burns-Bay-Road-Overpass-type-of-woman so, really, I think I'd have no choice but to take the example of one of my characters, Roley Nancarrow. Roley Nancarrow, he stopped eating and he stopped drinking. However, I know full well the hardness of that path. Although I only met the charming writer and mother of mountaineer, Lincoln Hall, once, I was to see her face on the front page of the Sydney Morning Herald a few years later. She had terminal cancer and her face was this blaze of outraged anguish because the only choice she had to escape the agony ahead was to stop eating and to stop drinking and I will never forget the look on her face. Gentle and witty Norma, how dare there have been no alternative.

If only I could, I would screw up that hand-penned letter to Pyne or "Mr Pyne" I'd now elaborate, "if you've ever been put under a general anaesthetic, isn't it a marvellous thing in the hands of a kind anaesthetist?" And in my experience they always do seem to be exceptionally kind doctors,

anaesthetists, they're kind of chatting to you about how what's ahead is like a good Merlot or Shiraz and then you just are out like a light and out of pain.

I'm going to ask you to forgive me one last time for ending with yet another nod to the loving example provided to us by dogs. I'm ending with this for I believe that to die at home with my head in the lap of somebody I love would take me unerringly to somewhere friendly far faster than dying a natural MS death.

This is the first stanza from the Bruce Dawe poem *Somewhere Friendly*.

Somewhere friendly  
the old dog staggers to his feet  
and the mange leaves him forever,  
quits his hide like a dream,  
and his cataracted eyeballs quicken and shine  
wall flower-velvet-brown  
and the youthful saliva returns  
and rolls like quicksilver in the dust by the road's-edge  
and his teeth glisten bonewards.

It's been a real privilege to speak with you all here today, thank you.