

Death Diminishes Me - Transcript

Produced by Gareth Watkins for Radio New Zealand January 2009

Time	Voice	Transcript
00:22	Actor	Why do we hate ourselves so much?
00:31	Howie	I love the thrill of unsafe sex – it gives me an adrenalin rush to know that I can see how close to endangering my life I can get without actually killing myself, instantly.
01:03	Actor	Men break.
01:11	Ian	It started out as a rather sick joke after a drunken lunch with some friends. We had skived off work, and we had spent about three hours having a very alcoholic lunch and about three or four houses / shops away from us was St Stephens Fulham Road – the big hospital there in London and none of us had been to a clap clinic so we thought it would be incredibly funny to go and have a look in one, see what they do, and even more important, see if there was anyone we knew in there. And so five of us went...
01:45	Shane	Infection.
01:46	Ian	...and we went through the whole rigmarole of being tested for every sexually transmitted disease under the sun, and then wandered off not thinking anything more about it. And after a two-week period one of my friends phoned up and said “Look, Ian, you are not going to believe this but I came back positive...”
02:08	Shane	Maybe I could pinpoint the infections to maybe three people...
02:11	Ian	...and then another friend said the same thing and another one...
02:15	Shane	...One of them was a friend of mine I had invited home and I noticed he was taking a fairly long time...
02:22	Carl	Infection.
02:23	Shane	...to actually go from block to block – we had to stop and rest – and at the time I really thought it was just the flu...

02:30	Ian	...I thought well maybe it would be a really good idea if I went and checked my results...
02:33	Shane	...I would imagine I was wrong, I never really saw him after that for much longer. He was pretty ill on that day.
02:40	Ian	...I was positive as well. It ended up that all five of us were.
02:52	Actor	Red and yellow and green...
02:58	Howie	Well, death wish...
02:59	Actor	... and blue. A death wish.
03:05	Howie	First started when I came out and was totally abandoned, so I did everything and anything to try and end my life. I felt alone, unwanted, unloved – not feeling worthy. Having a death wish.
03:42	Carl	Infection.
03:43	Shane	Another time might have been when I stupidly took a ride from someone, only to find that there was somebody else there and they basically took turns holding me down. I didn't know what was happening. I didn't even know that what had happened was called rape I just felt ... well I know the word to be violated, I suppose. Needless to say, neither of those two people are around anymore.
04:22	Shane	Night sweats. 2.00 a.m. freezing...
04:34	Howie	I had been feeling...
04:38	Shane	...very cold, very wet.
04:44	Actor	Memories – past and present.
04:50	Howie	Oh, scary. Oh, yeah I was nervous. A bit all shaky...
05:01	Shane	He stood up and ushered me into the room...
05:04	Actor	Infection.
05:05	Shane	...and he beckoned for me to sit down...
05:08	Howie	...The doctor asked me...
05:10	Shane	...“Have a seat”...
05:12	Howie	...if I had a fair idea as to why I was feeling ill...

05:16	Shane	...well, you are HIV positive. And he stood up...
05:32	Howie	...I was angry. I was sad...
05:34	Shane	...so I stood up...
05:35	Howie	...I was scarred.
05:38	Shane	<p>...And he came round to the front of the desk and patted me on the arm and said "Now, don't forget to pay the receptionist on the way out", and ushered me towards the door.</p> <p>He obviously had no idea how to tell me. Anymore than I had an actual understanding of what he had just said. So standing outside his door, I turned right and walked out of the office. I didn't pay.</p>
06:13	Howie	I tried to act tough and thought I would be fine. And so I left and then I realized I didn't have any real strong support and my world was just turned upside down.
06:44	Actor	Fear of the stillness over-rides all fear.
06:52	Shane	Who do I tell...
06:57	Carl	One's self-esteem, I think, really gets knocked when you are given an HIV diagnosis...
07:03	Shane	...what do I tell them?
07:05	Carl	<p>...Part of that is because you are blaming yourself. You are giving yourself a hard time. I think you are well aware that if you had practiced safe sex you wouldn't be in this situation, so you are very hard on yourself.</p> <p>You struggle for years to make yourself have high self-esteem and you have to sort of go through the whole process of finding your self-worth and maybe getting a job that picks you up and makes you feel like that you have a worth in life and then all it takes is a HIV diagnosis and you can be back to square one where you don't appreciate yourself and you are giving yourself a hard time and I think it can take years to actually bring back your self-esteem. I know it did for me.</p>
08:20	Actor	We use our memory as a way of reclaiming what has been taken away. To value even the feeling even of loss, is to value life itself. And so, to begin to live again.
08:40	Howie	I grew up in the Wairarapa in a small town called Masterton. Small town, small minds. I started escorting on the "beats" which is where gay men go to look for other men for sex, and I was paid for

		<p>it. Which was hard because sometimes I picked the wrong guy and got abused for being gay and also being a prostitute.</p> <p>My parents found out when I was fifteen that I was that way inclined. They disowned me so I had to try and find ways to support myself and find a place to live on my own. So yes, that's how the death wish came about.</p>
10:02	Actor	1985.
10:04	Carl	<p>There was this whole desperation just to live. Which meant you wanted to go out as much as you could. You wanted to go to as many shows as you could. You wanted to go to as many parties as you could and you wanted to dance as many nights away as you could. Sleep became something that I resented. I resented having to go to sleep because I wanted to be out and about because I felt like there was no time to waste.</p>
10:40	Shane	<p>To begin with I didn't have a future. I didn't even imagine a future. And I went through - I suppose you would call it a passive suicide where I just thought well, maybe I should just stop taking those tablets and let things come to end.</p> <p>I mean, I had caught pneumonia and that was enough to let me know that this was probably the end so I stopped taking the tablets.</p> <p>I can remember lying in bed in the hospital getting moved closer and closer to room number one – which is where you finally go home to die.</p>
11:27	Actor	<p>Eventually these things – muscle and flesh that characterize our individuality - will fall away and we will be brought back to that opaque density that makes the body generic. Our bones in death all weigh the same.</p>
11:46	Carl	<p>I think my Mum made me promise that when I got sick and needed to be cared for, that she would be the one to do that and look after me at the end.</p>
12:07	Shane	<p>And in room number three one day I remember not breathing. That was interesting too – thinking oh, I haven't taken a breath for a while.</p> <p>It got all dark and I thought goodness something has got to happen, I am just a little bit too tired to take a breath. But all of a sudden my body on its own did that great big gaspy thing and started on its own. But that was, I would say, that was close – very close.</p>
12:39	Ian	After two years I made a suicide attempt...

12:43	Carl	Coping.
12:45	Ian	...Being pharmaceutically inclined, I took a large cocktail of readily available pharmaceuticals that were designed to send me into liver failure. I managed the liver failure, but somehow I didn't manage to die...
13:05	Carl	Coping.
13:07	Ian	...It had just reached the point where I was just fed up and had had enough thank you very much and I would like to go now.
13:22	Rod	<p>Suddenly your life has stopped. Nothing's ever the same. The person you always talked to is no longer there. The person you felt comfortable just being beside, just sitting with not saying anything, is no longer there. And nobody really understands.</p> <p>So you have to pretend and you have to laugh and joke. It makes you want to wind the clock back. Go back and do things all over again, maybe different, maybe the same. But you can't.</p>
14:30	Shane	Eventually, as my friends started going - dying, suiciding - I think maybe after the fifteenth funeral I started getting to a point where I had seen enough. It was another funeral and another funeral and another friend gone.
15:05	Rod	<p>He had it all planned out. It was exactly what he wanted. What music he wanted. And he wanted "Send In The Clowns" to be played as the funeral started.</p> <p>And at the funeral - I was a lay chaplain at the time - so there I was in my little white robes walking up the aisle to the coffin ahead to the tune of "Send In the Clowns", and I had to laugh because I thought that this was his final revenge on me - that here I am poncing up, all made up in white robes and what have you, to his favorite tune of "Send In the Clowns" and the biggest clown of all was walking up the aisle.</p> <p>Shortly after we started the funeral, the dogs which had been kept in the car, got out of the car, and they came running into the chapel - and ran right up to the front and sat underneath the coffin and I was unable to continue.</p>
16:34	Calum	I held them. I held them as they looked at their flat-mate on the hospital bed dying. I held them as they looked at their son in his coffin. I held them and let them know that I cared. I held the couple, one of whom was dying, the other of whom was crying. I let them know my care, my support, my compassion for them - that I was there if they needed me. That I was there for them.

		<p>I held her gently. I supported her. I held her out of compassion, out of care. Showing her the support that I was offering for both her and her son.</p> <p>I held him. His skin felt soft, warm, yielding. I held him with care. I held him with compassion. I held him in sorrow.</p>
18:24	Shane	So many funerals... and nightmares. My goodness, the nightmares were just horrific. Going over and over whether it was perhaps me who gave it to them or they who gave it to me. Just felt a bit guilty about seeing them all go.
18:55	Actor	1992.
18:58	Carl	<p>It was a pivotal year for me in my journey with HIV and AIDS. By that stage I knew that both my ex partners were HIV positive and one of them I was looking after 24 / 7 as he had an advanced case of dementia, and if he didn't have someone looking after him 24 / 7 he would have been in hospital and that's one place he didn't want to be. He wanted to be at home and he wanted to die at home.</p> <p>So it was towards the end of that year that my previous partner, he passed away with an AIDS related illness, and three weeks later my partner at the time, he also passed away. I think I was left feeling incredibly drained, exhausted, alone and I don't think I really had much idea how I was going to even pull myself together at that point.</p> <p>It was just a lot of work just to exist and keep going on a day-to-day level after having cremated both my ex's. But having done that, I had to deal with myself and the emotions that I had been ignoring because it was easy to ignore when I was caring for someone else... their needs - it was much easier to put their needs first, before my own.</p> <p>So come the end of '92 I had to sort of look at myself and how I was going to pick myself up and live the rest of my life. And at that point I think I presumed I would only have another five or six years of life because ten years seemed to be the average life expectancy of someone with HIV. So it was sort of needing to make the most of what I had left really.</p>
21:41	Shane	<p>Infection.</p> <p>I think to begin with when I walked down the street, knowing I was infected, I would be aware of people looking at me differently. You shake their hand or you kiss them, and you think they must know, they must know. Look at me.</p>

22:11	Actor	What connects me to these people, what connects us all, is the body that faces its own mortality. The community of the flesh, open to death.
22:32	Carl	I think the hardest thing about forgiveness is actually forgiving yourself - with HIV. Forgive yourself for becoming infected with HIV.
22:45	Shane	<p>Forgiveness.</p> <p>I forgive myself for the stupidity and ignorance that I put myself through and I forgive the person that passed this on to me. I hold no animosity towards anyone. Oh, goodness how do I say this? I would hope people would forgive me if I put them through what I am going through. It was unintentional.</p> <p>Isn't it funny – today you feel like there is no excuse for becoming HIV positive with all the messages that people have. And back then, I knew nothing.</p>
23:54	Carl	<p>1998.</p> <p>My body sort of pretty much packed up with HIV and I went to see an HIV specialist in Melbourne...</p>
24:07	Shane	“Have a Seat”
24:09	Carl	...I was expecting to be told that I was going to be dead pretty shortly because I knew that my body was packing up and I had not kept in the loop with HIV or the medication, so I was pretty surprised to find out that there were new medications available and that I was going to get well. And actually go on to live for a lot longer. All of a sudden there was a lot more hope for the future, that's for sure.
24:52	Howie	Hope, for me, it keeps me going every day. Trying to live my life to the fullest as best as I can. Live better. Act better.
25:08	Carl	<p>For me at the time, not only taking the medication was life changing, but it sort of meant that I had to completely rethink my whole life. In a lot of ways I'd just sort of done quite short-term work, or never taken my job too seriously because I didn't think I'd have it too long.</p> <p>And then all of a sudden I was faced with the fact that I was actually probably going to be around for a lot longer than I anticipated and consequently would have to work for a lot longer than I had anticipated. So for me I had to completely reevaluate where I was at and where my future was going at the point.</p>

		<p>I remember being at work and somebody saying to me “But when we employed you you weren’t ambitious”. And I said “Yeah, that was before I was told that I was going to be living for the next twenty years.”</p> <p>All of a sudden progress and doing well on the work-front became actually really important to me, and something I had to get into because just doing menial work wasn’t going to be the answer for the next twenty or thirty years.</p>
26:39	Ian	<p>I have made a conscious decision that I am not actually going to take any life-prolonging medications. I am not going to take any prophylactic medications. I am just going to allow the virus to take its natural cause. Which in some people’s view of the world, the implication is that I am doing a suicide trip by not prolonging or taking any measures to prolong life. I personally do not see it that way. But I certainly wouldn’t consider actively taking any measures to end my life.</p>
27:31	Shane	<p>We learn from our mistakes. I have. I have learned the hard way. But I have learned.</p>