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Trevor Moore in conversation with Melanie Reid

Interview transcript

**Trevor:**

Hello Melanie, many people will be familiar with your story either from your spinal column in The Times, or more recently from reading your book ‘The World I Fell Out Of’, but perhaps you would like to explain the life-changing event that happened to you in 2010? In your book you say “I nosedived from the upperworld into the lower one”.

**Melanie:**

I was 52, I was fitter than I've ever been, and my son had gone to university. I was free and happy; I was a mistress of my own universe. I was partaking at the bottom end of a dangerous sport, I had done all the safety stuff but my horse refused a jump, a little cross-country jump. I nosedived and landed, I did a faceplant and my body flipped over my back and I broke my own neck, I broke my back too. It was it was like a nuclear explosion because I was paralyzed from the C6-7 vertebrae in my neck which meant I was paralysed from the upper chest down. My hands are very damaged, and I had to learn to live again. I had lost my life, and I lost my body. My family were also destroyed in this explosion and I felt I had entered a parallel world, which I don't think anybody ever really realises exists down there until it happens, and until you join the people in the parallel world. There I was, down amongst the frail, the elderly, the vulnerable and the disabled looking up at the happy shiny people in the world that I used to belong to.

**Trevor:**

In your book, you refer to yourself as having been The Times unofficial pro-euthanasia correspondent. I think that was in a letter or an exchange that you had with someone. How has your disability affected your position on assisted dying?

**Melanie:**

I was always in favour of self-determination and I had witnessed my own mother who had vascular dementia. I had seen her desperate to end her life and in fact, that's what she did. She took her own life when she was in the care home and I knew the courage and the bravery that had taken. I had heard her prayers, and she said to me that she didn’t want to go on like this.

I knew exactly what it meant to be kept beyond your life and your life span that you were enjoying. When this happened to me, I had this enormous residual knowledge of what it meant to be trapped in a body that you didn't want to be in any longer.

I had grown up in the 60s and 70s early 80s when a woman's rights were total and I was a feminist. I don't use that word in the sense of a device of sense, I think all women now are feminists, all women now believe they have a right to control their own bodies. I had grown up fighting for the right for contraception, fighting for the right not to be fondled by men or bullied by men and told what to do by men, not be told I have to stay at home and look after children. I had always been a bit of a rebel and that was in my jeans. This was obviously genetic from my mother too so I wasn't in any way going to have my right over this body that I live in taken away from me. In this explosion I lost that right, I lost the ability to be able to control and move my body, I became doubly incontinent, I became dependent, I need to be washed and dressed in the morning. When this happened to me, I knew instantly that my right to decide what happened to me was mine and no one could take it away.

It was a total conviction on my part and I would never ever seek to impose my views on anyone else. This is about my rights and I have total respect for people with similar injuries to me or who are disabled in some way, who are who are ill, but they choose not to go down the euthanasia road or even to have it as an option. I respect them in the same way that I respect people of faith who make the decision on a faith based way, but I would ask them only to give me the same respect in return, to make my decisions, not to interfere in my life.

I think euthanasia is also about love, it's recognising that if you really really love someone you would want them to be free and they want you to know that they loved you when they went out the door. Loving someone is freeing them up to do what they want to do and the hardest thing is leaving love, but people know when it's right and people who love you know when it's right. They want you to be free of pain and suffering and the discomfort, the appalling discomfort that comes from having a body that's not healthy. That sense of being locked into a body that is a prison - we all want to set people free from prison. We rehabilitate them and set them free so we should give people the right to make that choice.

**Trevor:**

That's interesting because you've touched on this in your book, about how really everyone's disability is relative and individuals might have their own particular threshold as to what the impact may be on them individually and it's not something that you can say will have a uniform impact on the way they see their life. I just wondered what you would say to disability lobbying groups who proport to speak for the wider community about the so-called slippery slope and so on.

**Melanie:**

We all possess our own disability, there are all the answers under the Sun, and there are no two disabilities the same. No two people react the same way to their disability and to the kind of prison they feel themselves to be in. Some people don't feel imprisoned at all and that's wonderful, but only we know what it's like, only we know what it's like to inhabit our bodies and how we react to it.

I personally do not want to be put in a tribe by anybody else, nobody has the right to label me, put me in a pigeonhole or put me in a box and say oh she has a spinal injury, but she's ok, she can get around in a wheelchair, she has people to love her, she can carry on. Nobody has the right to tell me at what point in my life is livable, endurable, enjoyable, that belongs to me. Just as it's my right to say I choose to go out to the shops today, I chose to have a baby when I was 32 or whatever it was, I choose to eat chips tonight, I choose to have a love affair with this person. These belong to me as human being, as an individual human being, they do not belong to anybody else who does not sit in the chair that I sit, wear the shoes I wear that do not work. The tread on my soles is completely untouched, I don't walk anywhere in there but I wear them. Until people know what it's like to wear those shoes that never walk anywhere, they have no right to pass judgement on how I live my life.

**Trevor:**

There is another aspect to this, our patron Paul Lamb is in the process of bringing a legal case against the government to allow assisted dying, following on from Tony Nicklinson’s case a few years ago. He's adamant that laws should help the incurably suffering as well as the terminally ill but he is clear that he doesn't want to die now and for him it's about bringing him certainty for the future. I just wondered if you empathise with that, and can understand where he's coming from in saying that?

**Melanie:**

I totally understand that some people are having a good life despite their difficulties, as I am, and they would like to continue doing that. I really love my life, well, I don't love it and I have I have great difficulties with a lot of it, but I love the fact that I'm here to be with my husband, to see my son growing up, to see the friends I love. All I want to know is that when I don't want to carry on that I have the right to choose. Like him, I just want to know that when things get too bad, I have that choice and in fact knowing that I have that choice makes my life easier. I can be happier because I know that if I start suffering really, really badly that I can say I don't want to go on with this anymore.

Funnily enough when I came out of hospital and I first came home there were enormous challenges in getting to grips with living in the house where I had previously been able bodied. What I did was, I built up a little stash of pills. I called it my suicide stash and it was a stash of benzodiazepines, I knew I had so many of them that if I chose to go there, I could have a nice and quiet end. The fact that I knew they were there, sitting in my little old pill box, well, my big pill box now, for me, it was my insurance policy. It was my security blanket and gosh I was glad I had that because that is what enabled me to say ‘right what are we going to do today? We're going to have a good life; we’re going to make the best of it’. You can't make the best of it until you have the right to know what the worst of it is and you can open the door and leave. That's my belief.

**Trevor:**

It’s interesting you say that, because in those jurisdictions that do have a laws permitting assisted dying, often those who ask for help don't avail themselves of it, but they find precisely that, they find it brings an element of control back into their own life knowing that they can make the decision when they choose, not being told by someone else.

**Melanie:**

I have very little control in my life in the sense that I'm very powerless. When you end up paralyzed and, in a wheelchair, you lose a lot of your power, authority or agency. That power that I have, that little bit of control, that knowledge that my fate will not be decided by anyone else and that I can choose the time for good death surely that is the one bit of agency that I'm entitled to. I don't want it for anyone else, nobody wants it for anybody else, we just speak it as individuals as a democratic right. For us, as one human.

**Trevor:**

Indeed, I think in California their legislation is called the ‘End of Life Option Act’ which I think is an accurate description.

**Melanie**

Yes, I think that is wonderful. Perhaps we could start putting pressure on our MP’s for that here too.

**Trevor:**

Yes indeed, and when our Parliament last considered legislation in 2015 one of the most common reasons for opposing a change was the protection of vulnerable people, such as those who might decide to ask for help, if they feel they are a burden to their families or their other loved ones. I just wondered what your response might be to the MPs who voted that basis?

**Melanie:**

I understand why MPs feel they have to protect people, that there is this concept of the frail, vulnerable person who they feel could be swayed by a bullying greedy family in order to pop-off and leave their inheritance for them. You know that it is absolutely right that society should react in that way and say, no we have to protect people who are not as strong and as articulate, and in control of their destiny as you and I might feel. However, we live in a society with incredibly clever lawyers and doctors, we have philosopher's, we have an absolute residual knowledge in this country on how to draft humane protocols that would make sure that nobody was at risk of being been hustled off their life. We have power of attorney, and the effort you have to go to get power of attorney is significant. We can put in place strong legal and social requirements that will act as an insurance policy.

**Trevor:**

You touched on this earlier, about your early life and I think you were touching on contraception in the 60s and that sort of thing. I think Polly Tobyn likens an assisted dying law to that for abortion rights back in the 60s, in terms of effecting major social change. Maybe this is the last one and I just wondered if you had her perspective on that?

**Melanie:**

I think absolutely, we decide what we do as young women. We decide how we live our lives. When we get to the end of our life, why should we not retain the ability to make that final decision? It's totally illogical apart from anything else, it defies the civilized society that we live in. The continuity of choice and decision making the anybody has who lives in a free society.

There is a suggestion that we should have built-in to any legislation a 6-months limit, so that when you knew that you had only 6 months left, you could make the decision you will be allowed to have an assisted suicide. My problem with this is that it is totally arbitrary because nobody can tell you for sure when those 6-months are up, when those limits come. It's one man, one woman, one doctors decision or opinion, but nobody knows. They don't know, you hear of people who live far, far longer than is expected and you hear of people who go much more swiftly.

I would make the analogy of young women. If you are having a baby and you're told at the beginning that there is always the option that you can have an epidural if things get too tough, but you can have the baby however you want to have it. You can have it pain free, gas free, without any medical intervention, if things get a bit tough then that option is always there for you, whenever you want it. We hope you don't need it. We hope you'll come through the other side with a healthy baby, but it's there if you need it. I think we should approach this legislation in the same way and encourage people to think - hey if my personal circumstances are such that, I didn't expect to go down this way, but I really need help right now and I want it and this is the right decision for me. Give me pain relief, give me an escape route, then it’s there.