Excerpts from Transcripts compiled.

Male, Candanian Man

My brother had breast cancer too. So you know the geneticists? They're fascinated by me, and my mother died of breast cancer as well. So there's clearly something there, but none of the genetics. None of the genetic testing has come back positive at all in any of the sort of normal genes. I suspect that in the next few years there will be some sort of bizarre, because I got a friend actually who has had breast cancer, and all of her sisters have had it, and none of them have the BRCA gene, so it's like it clearly does run in families and stuff, but they obviously haven't worked out the genetic make up of what that is.

My first call was to my brother and I just said, guess what I'm sitting in the parking lot here, and I've just been diagnosed with breast cancer and his first words were to me: 'Welcome to the pink world'. And I and I laughed, because I'd heard some of his stories about having to deal with it. He was a radio darling for a while, just because it was such an unusual story, and you know, headline grabber and I wasn't really that excited about that. But I knew kind of what I was getting into.

But my first real experience of it, and I I've told this story so many times, was after I had the biopsy's ultrasound mammogram sequence, sitting in the waiting room and clearly going to get a diagnosis of breast cancer. And I was handed the patient history forms. And so, I'm, sitting there in a room full of women, and I'm filling this thing out, and you know the first page is kind of typical medical history, and I flip it over, and I can't believe it. And I looked around the room and I said,'Excuse me, women, maybe you can help me with this. When do you think my first period was? And the room just erupted in laughter, you know. And I said, and I've got a follow up question, they want to know if I've ever been pregnant', and it just really struck me that the whole system was geared to women, and rightfully so. I mean the statistics are 1% of breast cancer is male, so it's very tiny. In Canada every year there are 20,000 women that are diagnosed with breast cancer and 200 men and so it, we fall into this kind of, It's a rare cancer, but it's not. And so that was sort of my first experience. My next kind of brush with the norms was meeting with the breast surgeon and one of the questions that I had prepared for her was to say how many men have you done mastectomy on? In actual fact, it turned out that that was indeed the person in British Columbia that does men, and her words were immortal for me. They have really characterised the whole journey. So when I asked her, her response was too many, and I just thought, yeah, this is the lady I want carving me up, and she said, 'I've done it several reconstructions as well'. I said, 'Well, you don't have to worry about that with me. Whatever I lose, I lose, and that's it'. That was my second experience that kind of really stuck in my mind. The third experience was once I sort of.

Once I had the mastectomies, they chose to put me on Tamoxifen. and I teased my oncologist at the time as there was no research that showed that Tamoxifen was effective for man. It was simple. All the research had been done on women. Men had been excluded from all the trials and that was where, at the time I was starting to get interested in a little bit more advocacy and paying attention to sort of what was going on around me, and so that was the next kind of time.

I've met 2 other men apart from my brother in Canada, one a journalist from Toronto, and the other one a man who dropped into a support group and he never came back for whatever reason but it was an advanced cancer support group, and he had advanced breast cancer. But it was, you know, I've slowly accumulated the stories and and it's been interesting because I kind of keep a toe in that world. But for me a lot of what happens is, I draw parallels to my past experience with lung cancer and that is really a dominant part of my personal narrative because I see the huge advances in breast cancer research, and I did a digital story, a 3 min digital story on my work in advocacy, and it was sort of based around my mum's experience with breast cancer and just then I realised in doing that, I am not sure how accurate it is, but lung cancer research is where breast cancer research was 40 years ago. I mean it's just really that significantly different.

The other thing I guess I would do is I keep an eye open for various surveys. There are a couple of us on Twitter, that post regularly about breast cancer research and raise the question as to whether men are being included or not. And in the States there is a directive from the FDA that unless there is a very good reason for excluding men from breast cancer research that they are to be included which is interesting. I think that speaks to the heart of an issue.

Researcher

I was interested in what you were saying about. You know the that I I don't know if this was correct me from wrong. But when we spoke online, and you were kind of saying, you had to suggested to me that I check with the other women if it was okay for you to be included in the workshop and see. To be honest, I hadn't even thought that that would be a problem. I really didn't, because for me, as someone who has had breast cancer I would have no issue with that. But I didn't think about how it is for many women.

A Woman's experience is a very intimate. A lot of it is to do with you know identity, and I haven't thought, and I've experienced all those things as well. But I haven't really, thought I, just for me if there was a man in the room, I would still be able to share that stuff, but I haven't really thought about it, and then it really made me think about how that must feel for you? I'm really interested to understand like. How did that affect your identity? How did that make you feel like coming away from the work you've done, and the advocacy and the research, and all that, like as a human being? How does that make you feel, and how does it affect your identity as a man in this world that is so female dominated?

Participant

That is a really interesting question. I always struggle with identity questions for whatever reason. But I would point to a couple of different things. First of all, part of my experience is my wife dying of pancreatic cancer, and so I was diagnosed with breast cancer and lung cancer. I went through treatment. I had my mastectomies at the end of August at the beginning of October she was diagnosed with pancreatic cancer and 6 weeks later died. So I call out my crash course in palliative care.

But it was really the story I like to tell about kind of what that was, and maybe that's what my way of expressing my identity is through stories, but is me. I think it was early August. Maybe, it was even earlier. Maybe it was just before I started treatment, but me standing in the bedroom screaming at, or you don't get it. I'm going to die. And I mean I've been given these really poor prognosis for my disease, and you know I'm facing 2 of them, and it just did not seem very hopeful at all. And about a week after her diagnosis she was standing in almost exactly the same spot in her bedroom, and she screamed at me, Angus, you don't get it! I'm going to die. And it was just one of those, and then we burst out laughing at the 2 of us because we realized kind of the similarity, the challenges of our situation, and it was really. I mean it was. It was a beautiful, gentle time. It took her by surprise, but she handled it really really well, and we had a lot of support along the way, and it was really, I mean her death. Ever a beautiful experience.

I don't know, but I I think a genital death is is what we all kind of hope for, and hers was. We celebrated our anniversary

The second space I would talk about is is support groups. There were 2 occasions on which it really, I asked about participating in a breast cancer dragon boat which is a big deal out here. I don't know if that's a big deal in in Scotland, but out here they call them dragon boats. It's a Chinese kind of it's a long boat. It takes 8 paddlers 8 to 10 paddlers and a steersman, and they race essentially, and it's become a really strong school for breast cancer patients, first of all, to get together and do something physically. They practice a couple of times a week together, and just bond in that boat. And it's also a good way of getting that muscle tissue and the paddling exercise that is really good for breast cancer patients and I was told that no as a man, I couldn't do that. And so that was one of my experiences of exclusion, that kind of well, I get it you don't want to give some team an unfair advantage, because they've got a man on the team. But there's no way with 200 men a year just diagnosed with breast cancer in Canada that I'm going to be able to put together a male breast cancer team, because that's never going to happen. So you know it. That was one. And the second one was a little more, so it wasn't subtle. They were very blunt with me and that was my first experience where I had. I asked if I could attend a breast cancer support group, and the facilitator had never had to deal with the man asking before, and

she said I'm going to have to check with the women because we talk about some pretty intimate issues, and they said No. And that was that, that was my first experience of it.

It still shocks me that when people make comments about well, I didn't know men had breasts, that sort of thing. But I think that the funniest thing was the question that I was asked in that history form at the beginning of you know, when was your last period, and I mean it was not somebody asking me that directly, because I think they would have not asked it. But given the form and asked this in a medical history question about a pregnancy and about periods.

While I joke about it, the fact that there was no research to back up the fact that I was being given Tamoxifen bothered me a lot, and I think there was an underlying current of anger with that really.

Women in 40s talking about Covid disruption and addiction/trauma.

Well from finding the lump to treatment was like being plunged in a the darkest whole and my first concern was. Okay, you've got. You've got a lump and I knew intuitively it was breast cancer, and you. I knew it for a while. But I didn't go to see about it, too. Because I was frightened of what they were going to say. Because I knew that life would change. Doing anything I could imagine at that time, not having enough support for my disabled son to even get to the, to the GP. His care needs came first. And eventually it becomes a pattern. When I was looking at myself, I just was. I could see myself in the mirror. I thought, you are fucked. And that's when I was like that. You need to go, because I knew that I had cancer. So then, going to the doctor and the doctor knowing as well as I did. And her saying, you know what that is don't you? Yeah, she said, okay, i'm gonna send you fast track. Your going to get into the hospital. And who is going to look after my son when I die was the most important thing, because there was no other way. All I could think was I was going to die. And who's going to look after my son, who's profoundly disabled? And it was the first time I'd thought that. From what was going to happen when my son died, to now it was going to be who's going to look after my son when I die. And then who is going to come with me? Because they said you should, you know, take someone with you.

I'm going up to the hospital, how frightening it was, being told on that very day, 31st October, you have breast cancer, and it's in your lymph nodes as well, and we don't know what type as we want to test it. And coming home and my boy was in a wheelchair, dressed as fucking Dracula because it was Halloween. And just my, that is the most heart-breaking, to tell my children. And not having a clue, not having a clue, how things are going to fucking work out for these kids? And then, of course, Covid hit and Covid caused more disruption to me than anything else. And so I started off that was that, got it, got the results. And it was you've got a very aggressive form of Breast Cancer, and we need to know if it's spread

through your body. And of course, I believe it's spread through my body, because all the pain I was in. So that all of that insecurity, all that head work. Yeah, it's in your body. It's all over your body. You're going to die very soon. They're going to tell you after they look for all that they need to look for. I was going for all the different tests, had to tell my family who are completely dysfunctional. I have to ask for help, which is something I've never done before, rely on other people, yeah?

And then, of course. with Covid they stopped my chemotherapy which was so fucked, because they had gone from, you need to get this chemotherapy to give you the best chance of living to, oh you don't really need to get that chemotherapy, which was just awful, as much as all of the treatment. I went through the radiotherapy. Stopped me working, stopped me being able to do anything in the house. I've never ever done that before. I'm having to get my son, my older boy, to move into the house to look after his brother and me. Tell me, after surgery, that they'd taken out the lump, didn't have anybody. Because of Covid restrictions. No support whatsoever. I got let out the hospital, carrying my own bag, with no strength, no even a porter, to bring me down because of Covid. The women, the nurse waiting outside, standing crying because she couldn't help, and they wouldn't let her in, just to even bring me down

And then ringing the bell, but my family were not allowed to be there, which was a huge thing for them, because that's a signifier that everything is going to be okay. But it wasn't a case of everything is going to be okay for me, because I knew that there was still other work to be done: radiotherapy and all this stuff and having to do all that myself and just feeling completely alone in it. No having a partner to attend anywhere with me, the strength that male, masculine strength that I needed at that time to tell me that I was going to be okay.

And then the residual effects of it which for me was in my mind. We are questioning every ache, every pain, constantly, constantly feeling my breasts, constantly feeling for lumps. Feeling my lymph nodes. In my mind I was, you know. And all this access, this all online because everything was stopped because I couldn't go to anything. No support groups or anything like that in this online meditation thing, and it was just like I can't meditate, because when I meditate, I feel as if I'm … and I can see like I'm bringing cancer to me. I would meditate, and I would see cancer cells join in together. But I can't stop that stuff, you know, literally right down to my mind. I viewed everything through a cancer lense and everything was well, I was just really really fearful.

I ended up with all sorts of conditions as a result of cancer, and I've been registered as disabled as a result of the treatment from cancer and it has really affected every part of me, because it's changed me completely as a person. It's traumatising. And I think that's the thing. It is a trauma, just like all the, Oh, yeah, you are amazing, you are so strong. What else can I be like? I just got on with it. I didn't have any other choice. Its a trauma, and I think that's the thing it's like I remember the end of it. It was just like talking about the bell. They had to disinfect the bell and then it was just me in a corridor on my own. There was one

woman at the another end, and I'm standing, and the nurse, who I had never met before took a video of me for my family and I'm ringing the bell, and when you watch you can see the tears were blinding me and I couldn't stop crying, because first of all, I feel a bit like I didn't know these people, and I just want my mum and my kids and it wasn't what I thought it would be at all.

In the beginning it was like I got chemo on a Friday, and I was hospitalized every single time I got it because I would be vomiting so much, but it would be the whole weekend, and then my mum, my mum or somebody, would come and help with the kids for the weekend, but then it was like, oh, Covid hit so we can't help any more. We're doing it for you, and I'm like, I know, but I need help. But yeah, Covid Covid in itself, was disruptive. And then you've got this 'unprecedented' situation, and I wanted to shout, but this is an unprecedented situation in my life. That's so important to discuss that, like the actual, the impact of Covid because the impact of Covid was huge for cancer patient. People were just left to die.

All my care was removed from my boy. They left me right, I wouldn't be hospitalised, but I'd end up in my bed so unwell I'd be all right on the Friday, up till about 9 clock at night and then be dead. I would not be able to move. Yeah, It just started happening and my nails fell out. My teeth started to crumble and my gums were plating all the time. I'm looking at myself, and I'm like what is going on here, you know, like my whole body, and I couldn't move. The chemo didn't affect me as bad as radio therapy though. It messed me up completely like. I've never come back from radiotherapy. And like you the pain of chemo and the pain that nobody talks about. Freezing going through your veins.

Middle Aged woman- long term health and sexual relationship

But I found that I just couldn't get back to work. I had to get early retirement, and that's to me a big part of who I was, because I just all these years. But you, like yourself, when I was younger. I had, because I had my kids and then I went back to train as a social worker. And then for 20 years it was my job, and I loved it and the people, and that's to me been a big part of losing my identity. I'm not, because I know I'm just not the same, and I'm just tired of it. I'm just, I catch everything that's going. My immune system is just shot to pieces, some people saying, oh, you and you mentioned this, that, but I've never been the same since I had the breast cancer. I mean, I want to get back to work. But I just, my doctors and the consultants said that there's no way I can go back, and I think I had to eventually listen to them and say, right there's no way I can do that. I am not the same person as before. I've no got the same energy, the same concentration span, things like that. So basically, I've been sick all the time, and ever since then I just feel as if I'm catching one thing after another, and every day is just, you know, really sitting in the house. I was watching my grandkids for a wee while there, which was great. That was too much for me as well. So, I ended up having

to say it was just, you know. Now, it seems to be every couple of months I catch something, you know. I never get a break.

I'll start to feel great for a couple of weeks or a couple of months, and think brilliant! I can go back to work. And then, all of a sudden I'm like bang again. But it's the ongoing effects that effect you. You know anything that people don't really talk about, about how you, having hormone receptive breast cancer can affect you as a woman as well, and all that sort of taboo. And so yeah. Because of this drug I basically had to get through the menopause all over again. So, it was like a double whamy. And then that affected the liver.

But I've been married for 32 years, and that, there's just nothing, you know. When I'm walking this walk, I have my husband to support me. But we've not got that connection anymore. You know there's just, there's nothing there. There's nothing there's now. It takes all of you.

I mean, I tried to speak to them. I don't really talk about it, but it feels like I'm a child again. But I've not got any room in there to feel any sensation. I've not got it. So I'm not missing it because there is nothing there to be missed, if that makes any sense. but you're trying, you know, up to a point. But that's how I feel, it's a sexual relationship. It was something we both enjoyed, and that's been taken away. We don't have that enjoyment, that connection anymore. We don't have, you know. And you know he doesn't say much. Obviously it's okay, but its not okay. This is, we are a couple. But I think he's just glad I'm still here. Obviously you have no closeness as such anymore. You feel more like friends, if that makes any sense.

I'm not the same person. Before breast cancer I was healthy. I had a good job, that I loved and very rarely got sick. And now since having breast cancer I'm, I just a shell of myself. I feel like I'm a lot older than what I'm at. But what gets to me about people, is when they say but you don't look unwell, you look good, and I thought, see inside, if you could just see inside. Never mind how I look outside. It takes me a lot, I know, to just even do normal things when it's at any time of day, even going to walk to shops. I got my bone density scan results through a couple of weeks ago, and that's showing that 20% lost since I started. So that affects obviously my bones, and how tired I get, and how sore I get. I'm now on tablets for the high blood pressure, high cholesterol, things that just never happened before. So I just feel as if my whole body is just collapsing, if that makes any sense, it just seems to be this. It's one thing after another after another. And I just don't seem to be getting a break. The long-term side effects has really changed my life. And I know it's just going to get worse; you know it's not going to get better. I'm still on these tablets for another 6 years. So, goodness knows what damage that's going to do in the long term. So yeah, I just feel that I might look okay and outside, and I can. You know people are like you look great, but inside I'm like, I can't.

Young Woman 26-Fertility

When I was 21 that's when we actually got together, and then we got my married, which was really nice and obviously Covid hit, and I was supposed to be going to America with my work, and then it got cancelled. But we had always said that when I came back, we would start trying for a baby, and that would be, you know, the start of us having our little family. That was in the July. So then August is when I started my appointments with the clinic and then, a few weeks later was diagnosed with breast cancer. So when I went for my appointment, where they told me I have breast cancer, I'm very sorry to tell you that. And then they passed you over to the nurse. We must have been with the nurse for 2 hours and had a few other tests and stuff, and at that time they mentioned the fertility clinic, and they said, you know about kids, do you want them? Are you planning on having children? And they were supposed to refer me then on that Friday to the fertility clinic. So I got them and 10 days later, I was like I've not heard anything from the fertility clinic and they're like, oh, we didn't know you wanted to go to and I was like yeah, we did. We discussed it. We had a lengthy conversation about that. And they're like, okay. So then, the next day basically we have an appointment, at another hospital. And they were like yeah, okay, this is great. We can work with you, even though you have the, you know, you've got polycystic ovaries, there's a good egg supply there. This is amazing and I feel some hope in this terrifying situation. We'll actually be able to start your medication today.

Just need to wait for this period and next week you'll be able to come up and start the injections because I didn't have a regular cycle. They were basically forcing my body to have one. And it was the first time in all of my diagnosis that we had this positive, clear sort of hope that we were going to be able to create eggs, our embryos, you know. There's so. It's so intense like you go up and you're brought in your room together. And you basically get the. Are you sure this is the right decision for you? And you're like yes, and then they like, they want to make sure that your sure. But it's still really like no one tells you that that's going to happen. And then it happens and your like oh, okay, okay. And then I've had a test. I'm doing the blood test and then we just have to wait. So, I started on these tablets, and I well... sorry I started reading the leaflet whenever we got it, and it said If you have a breast cancer please refrain from taking this medication. Is that okay? I'm confused what I do, and I phone them. They said that would be if you have had breast cancer and so it turns out we're going ahead. Okay, okay, no problem. That's fine. So I started on the tablets, and let me tell you, I have never had pains and sickness and all I do know was my body was like screaming at me, saying, what are you doing? It's horrendous. Absolutely horrendous. Period started happy days, and they're like, okay, come up on the Wednesday and we'll get you started with injections.

Monday got a phone call from my Oncologist and he just said, hey, can you come up for an appointment, I was like, yes, no problem that's fine. This is a little bit strange, though. Why, I have to come up for an appointment and went up on the afternoon, and they were like,

hey. So just want to tell you that you have inflammatory breast cancer and due to the aggressive nature of it we need you to start with the treatment like asap. And I said okay, but what about the fertility process? And they said, unless she can have it done within 2 weeks you cannot have it. I then was not okay, but by myself, I've just been told I can't have kids. And yeah, it's really challenging. And for me that was worse than being told that I have breast cancer, because in all of that that was our little glimmer of hope that was like a future. Yeah, that was like looking towards like the next step. So yeah, then, I have to tell my husband, which was like heartbreak. And because one thing he always said was, I don't want to be an old dad. He is 8 years older than I, but he lost his daddy when he was 32, and his dad was 50 whenever and Shawn was born. So, he's like I don't want to be an old dad. I want to be able to play with my kids and have fun with my kids and I've always had that. But I was like we'll have kids whenever we're both ready. Obviously, I'm on hormone drugs now for 10 years.

When I finally got speaking to the nurse like she, I'm so sorry, I'm so sorry. But again, it was having to re-live that experience of telling someone that you can't have a child and everything that you have spent the last week getting excited for, you know, I can't continue, because this thing inside your body is so aggressive that you have to decide between saving my life or having a baby. It was like, I have to decide, but I want to make sure that I am alive, or I want to make sure that I am like I picture. And I... I don't really know how to describe it, and I still have those emotions where, like, whenever friend tells me they're pregnant. Obviously, I'm delighted for them. I am, I'm like you know that's not us, and it's not that I'm angry that it, that we didn't get to go through with that it it's. It's a hurt. And whenever you like, long for something and you can't get it something that your body should naturally be able to do you for you and you cant have that. It's yeah, it's at it just brings up so many emotions. It's it's a challenge.

Because I had inflammatory breast cancer, a break from treatment, that's something that they probably would not consider until maybe I've been on it for 7 years, and with inflammatory by sensor generally, they don't like you to take it a break. Its not because I have to live with that every day. I have to live with that every time I see someone have a pregnancy like that. They'll live with that every time I buy a friend a baby gift, and I had 2 friends, and they gave birth quite close together, and I really struggled to walk down a baby aisle or pick up baby clothes and that was something I used to love to do. And then, now I cannot even walk up the isle. I just pick something up and get, and get home and shove it in a bag, and you know not have to deal with it. And it really, like it really does affect you and I don’t want to burden people with that either. Whenever you're feeling that way, so it's just like oh, it's all right. I'll get over it. No, I feel very much that it's just sort of like.

I think this might be worse because we didn't get to continue with the process had. Maybe we got to continue and knew if it worked. Maybe I would feel different. But yeah, it just felt like there was a bit of hope and then the rug was pulled. And yeah, because, you know. I

think the difficulty in being younger is, you've got a lot longer of your life left to live post cancer and all that comes with that men tally and physically.

Mental Health Condition, drugs and money.

In terms of more fundamental disruptions, It certainly changed my value system and changed not just my perception of myself, but it's a, it allowed me to challenge lifelong assumptions about the way I seen things. Yeah, and so if I go first to the first kind of disruption? Probably the way I felt about myself and you know as I said the first one was about my work, and I suppose for me it was ideas and how my values intensely wound up with my identity and I think that might be because I was an academic and I've pretty much been an academic all my life. It was for 35 years my actual career. And once that was taken away it gave me a kind of freedom to be able to look at the world without a scientific head on it on all the time. And that wasan huge change in my life.

Anyway, I could just remember being in Glasgow was brilliant, even though there was nowhere to go, and everything was closed and so on, that really helped my recovery. Yeah, disruptive in a good way with my treatment I guess. But then the surgeon told me back in January that I would have to take Tamoxifen for 5 years and kind of throwing that on me because they haven't mentioned it before. And I thought I'm going to put in all these drugs, how will that affect me? And when I said that, he told me again, and I said, well, but will that interact with drugs I'm already taking for bipolar? And he said, oh, I don't know. And then the nurse was in the corner immediately turned around, and she said, you better see you GP about that. And I said, okay. They strongly told me to take it.

So within 2 weeks I could actually feel it making me go, and I haven't had an episode for quite a long time. Bearing in mind, I've managed without any kind of episode. I could just feel it, so I, after 2 weeks I felt so ill, mentally ill, that I just contacted my GP and I said I'm not going to take it. And then the breast team called me and said, you know you really should take it. And I said, I explained why not. And then one of the breast cancer nurses said, oh, but if it makes you depressed, then you can just take some antidepressants. What I found was, it's just like you need to take this. It's going to save your life, and it's like well, what about this side of my health.

The GP was asked to try and persuade me, and I just said to the him and he did understood where I was coming from, and I just said you you're not understanding, I would rather get cancer again than live with the risk of suicide. You just don't get it. So. Anyway, I didn't take it. I'm not taking it, and I consider my risk to be much lower, in terms of my my risk of dying with suicide.

So then the next thing that happened was I was contacted by Macmillan, and it's called Improving the Cancer Journey, and it's partnership between the Dundee City Council and

Macmillan, and I was offered various services from them including 6 clinical psychology appointments straight away. No waiting. It's amazing and we phone benefit advice. By the time it got through to March I had no money. I'd used my voluntary severance, and I was down to the kind of limit before you go into universal credit. So, and I was terrified of applying for it, because I just thought I wouldn't get it. Universal credit is not meant for people like me, but he said it was as they helped me to get that personal independence payment too. I was at the point of having to borrow money from family and my mortgage. In fact, my mortgage is more now, but my mortgage was a £1,000 a month. I know I had little in the bank and no job being treated for cancer. I was just kind of rolling from one thing to the next, but MacMillan just picked me up in such a practical way, because I think people think of them as being kind of like emotional support. They tried their best to help me with my mental health crisis, but also without them I couldn't manage financially. I really was Rock Bottom.

In the end, my bipolar episode was about 18 months long. It was a mixed episode. It was horrific, and I came as close as I ever have to just giving up. I don't know if you're familiar with this, I'm familiar with living with suicidal ideation. It's just part of everyday life for me. It is a symptom of my condition. But I lost my ability to fight it, but I didn't even lose it, I just didn't want to fight it. I thought, if life is going to be like this, then I would rather die to cancer. I was living by myself. My sister lives in Canada. So, she was kind of face timing 3 times a day, and I don't remember a lot of it because I was so off this planet. But she says that some of those calls she made were 3 hours long and I was just not here, and she couldn't reach me. I didn't really have psychiatry support. I was trying out lots of different drugs and treating a mixed episode is really difficult, as you can imagine, because you got to somehow deal with serious depression and really big highs at the same time, and my moods were changing 4 times a day and I was psychotic. I was hallucinating. It just It was hell. there were some days where I remember I was just lying in bed counting every minute. That's another minute, that's another minute on, that's another minute on so that, well I stopped it. I knew after 2 weeks, you know you can, you become familiar with how it feels when the changes are happening. I could tell it was frying my brain.

I was so angry and I am not an angry person, but I was. It was like it was messing with my brain chemistry, I mean it does to many women anyway and those who haven't got mental health conditions. But if you have a pre-existing one, you know long, lifelong mental health condition you're not, you're you're not receiving that treatment in the same context as people without. So I was very, very sick.

Then another thing that was then suggested was the Macmillan Digital story project, which was kind of just starting then, and you joined a small group of other people with all different kinds of cancers. But they taught you all about storytelling and you chose your subject about what matters to you. That's kind of like our theme, what matters to you, and it was all online, obviously. And I decided to make mine about how cancer stole my mind because

that's what it did. And so that was just an amazing experience, it really put me on a different path for the rest of my life. People say, I think differently now about life now that I've had cancer, so I have that. But then I also have this other thing that made me able to kind of understand and accept who I was as a bipolar person with everything else in my life, things that I haven't accepted that I had. I wasn't prepared to admit how much bipolar had challenged me throughout my life, how much harder it had made my life and what I've gone through workwise in order to be a successful academic living every day with this. So there was a whole lot of identity issues to do with my identity as a bipolar person. And then what happened was when I finished my movie Macmillan people started looking at it, and one woman in particular, who is like one of their senior figures had a kind of passion that she wanted Macmillan to look at cancer care for people with long term mental health problems, both people who get a mental health problem because of their cancer and those already living with it. So that was really amazing for me.