

My name is Jolene and I was twenty-three when I was told I had malignant melanoma and may only have eighteen months to live.

Diagnosis

I was fine for five years. I went to university eventually. I graduated and it wasn't until after I graduated from university that I found out that I was then stage four. So I'd had five years of sort of having a normal young you know teenage/adult life before everything kind of came crashing down.

Interviewer: How did you feel when you were given that news?

Really angry [laughter]. Hard done by, unfair. It felt like why me, what have I done to deserve this? So I've had a brain tumour, a lung tumour. I've had two bowel tumours removed. Um I'm now on my fourth different type of chemotherapy, and I've had various lumps and bumps removed from across my body.

I think it's really hard to comprehend at twenty-three that you may only have eighteen months to live, but now I look back and I guess I should be quite proud that I'm still fighting on, six years on from that diagnosis.

Treatment

For the rest of my life, however long that might end up being I'll have to have some form of chemotherapy. Currently I take drugs which weren't available at, a few years ago. So you know I'm lucky in the sense that they are helping me and had this happened a few years ago I probably wouldn't be sitting here now.

I think timing-wise in terms of the treatment I've been receiving I've been lucky in the sense that you know actually new treatments are coming out, have been coming out faster than my cancer has been spreading or reacting. So you know I'm lucky that this is, this didn't happen to me in such a severe way. You know I'm lucky this all didn't happen to me when I was eighteen because I probably wouldn't be sitting here now.

My parents are separated, but I see them every three weeks when I go for chemotherapy back home. So it's a kind of a strange scenario I guess in the sense that they probably wouldn't see each other half as much if it wasn't for the fact that I was unwell, um but I need them

there for their support, and you know making it feel less horrendous than it actually is.

Coping mechanisms - living a normal life

Interviewer: So you've done remarkably well.

Yeah

Interviewer: [Laughs] And you're positive now.

I like to think so. Yeah definitely, I think a positive mindset has definitely helped. I just kind of want to live a normal life, like I don't really want cancer to be a big part of my life. You just want to feel like a normal twenty-something-year-old doing normal things, going on holiday, hanging out with your friends, getting takeaway on a Friday night, like going to work, you know socialising. Like that's really important because [pause] I don't want to regret not doing anything, and I think if I had stayed at home and stayed with my mum actually maybe I would have declined sooner because I would have given up, and no one ever gets anywhere in life from giving up.

I didn't want to be professionally ill for the rest of my life. I decided to get a job. I then moved to London with some of my friends from school, and I've been living independently and having that life for the last few years. So I tend to shut off being ill and, and kind of keep that very separate to my daily life as a young person living in London. Moving to London; I probably couldn't have done that without moving in with some of my close friends from school. I think it really helps to be with people that know you really, really well, um people that don't mind if you rant and rave or cry.

I don't want to be on my deathbed and think I've wasted all my time crying. I think at my age as well you just have to get on with it. You either carry on or you choose to admit defeat and I'm not ready for that yet.

Coping mechanisms - work

My friend Lucy said that she was moving to London, and I decided that I would move with her. So we moved in together and I started back at work two days a week, and then in May I started working four days a week. So I've kind of progressed gradually back to being in work.

Interviewer: But you were told when you were given your prognosis that you might only have eighteen months to live. Why on earth Jolene did you go back to work?

Work is quite important to me to maintain a, a sort of normal so to speak life and having something to focus on that isn't being ill is a big distraction and I really enjoy that. I work at Sadler's Wells Theatre. Um I work in the press and communications team. Um I really enjoy it there. My team that I work with know that I'm ill and they know the extent of my illness.

At work it's nice to just be another colleague and have some anonymity in terms of you're not the ill person. You're just another person in the team who's you know working with certain people every day, and people don't focus on the fact that you're ill. They just focus on the work that you're doing and they care if you're doing a good job.

Coping mechanisms - fitting in

At the end of the day I just want to be normal. I just want to be like everyone else my age. Basically you want to fit in, and cancer makes you an outsider in a world full of insiders. I guess putting makeup on is like, like putting a mask on, like I was never really that bothered about hair and makeup before. I didn't have any hair. And now it's quite a key part of my routine to make me seem like the character of the well person that I, you know I think everyone perceives me to be, and so the whole process is about looking like everybody else, it's about fitting in.

I feel like it was particularly hard losing my hair and losing my eyebrows because it makes me look ill. So you can't just walk down the street normally. You know if people see me they, you know, if people see me they would know that I was ill and I find that particularly difficult.

Interviewer: That's what you didn't want.

That's exactly what I didn't want.

Interviewer: You don't want to look ill.

No.

Interviewer: So tell me what you do to not look ill.

Um currently I wear a wig. I have my eyebrows tattooed. Um I wear makeup to cover up a lot of the red spots I have as a sort of a side effect of my treatment, um but it's amazing how much you can cover up the signs of illness with a, a few tweaks.

One of the best things I've ever done in this process is have my eyebrows tattooed. Um I kind of wish I'd known about it before they all fell out. It's not really anything to do with vanity. It's just to do with normality and you know fitting in with everyone else. I'm still wearing a wig right now even though my hair is growing back. Um I'm going to leave it a bit longer I think before I sort of get rid of the wig. It's funny how it's become a, I guess a bit of a security thing.

What I would like to do is I would like for my hair to grow really, really long and then do like a [laughs] big reveal or something, or eventually I will take it off, but I don't want to have a really dramatic transition. I don't want to go from really long, straight, dark hair in a wig to a short pixie crop.

Relationships & boyfriend

Yeah I definitely think that'll be nice but I've got cancer so I think that they won't be that bothered. I don't you know go on night's out. You know I don't go out to clubs. I don't you know socialise in the pub. So I'm not going to meet anyone, and actually it's easier that way. I think I've kind of put a lot of barriers up and [pause] if that's how I cope then that's kind of fine. So sorry if Prince Charming's out there.

Like I can't cope with it myself sometimes. I shouldn't expect that somebody else should. I don't think that's fair. I think how do you like introduce yourself to someone and be like basically by the way I'm dying, do you want to go out with me? It's not going to happen is it? Like everyone goes oh yeah it'd be fine. It wouldn't be fine. Like that's a stupid idea.

What have you learned?

I just think it makes me very, very, very grateful for the people that I have around me, and actually to realise that in amongst all of this I am lucky, like there are so many things about my life that are good. I guess I've learned [pause] mm, mm interesting. [Sighs] What have I learned about myself? [Pause] I would say patience but that's not true. [Pause] I think I've learned that I'm actually stronger than I ever thought I was.

A lot of people say to me oh you're so brave, you're so strong, and it's, it's not really about that for me, because I don't have a choice. Um but I guess, I guess I'm quite strong in that sense.

Interviewer: Are you quite proud of yourself with what you've managed to do?

Yeah. I'm really smug about it. [Laughter] If I'm honest.

Interviewer: Really?

I'm a bit like humph look at me, haven't I achieved a lot, like it's wh-, in terms of obviously being unwell and how I've sort of responded to treatment and how I've kind of overcome I guess a lot of, a lot of hurdles that you know other people would probably never experience in their whole lifetime.

Interviewer: Is it important to you that people think that you're strong?

Yeah it's really important that people think I'm strong. I don't want to look weak.

Interviewer: Why not?

Cos I think that's admitting defeat. Weak, weakness isn't an option. I'm a gladiator. I'm fighting.

Brave face for others

Interviewer: Do you feel as though you're putting a brave face on it or not?

I do feel as though I'm putting a brave face on a lot but actually if that helps me and if that helps people around me [pause] I don't really mind. I hate to see other people upset at I guess my expense. So I try to be as strong as I can because I don't want to be the reason why people are upset. I would definitely you know say that I'm playing a character. This character I guess is, is the person who's Jolene who's absolutely fine and there's no problems and it's all, everything's amazing.

I can pretend as much as I like that I'm great and I'm happy all the time and it's all fabulous, but we all know that the truth is it isn't but I'm kind of living in my own bubble, and if that makes me get through

the day then that's fine. I think the hardest thing is at night when you sit and think about things or you lay in bed and actually that is really, really difficult, because that's kind of when the enormity of the situation kind of weighs heavy on me.

You know I wouldn't wish this on anyone, like I wouldn't wish what I've been through on anyone because it's not pretty and it's not, it's not [becomes emotional], it's just horrible.

Denial and hope

I'm definitely, like definitely, in a bit of happy denial, but I know it and I don't really care. I've got to see a future. And even if that's only in the form of dreaming that I'm old and grey that's fine by me. Realistically no I won't be old and grey and eighty years old. Like I know that that won't happen, but actually I can dream that and I can believe that that will happen, because that makes me feel better. I do kind of have my head in the clouds, because what I actually hope is unrealistic.

In some ways I think it's quite healthy, because if I were to just admit to myself like oh I'm going to die and I don't know how long it's going to be I think I'd be worse off than I am now.

Interviewer: That you'd die quicker?

Yeah.

Sadness

Interviewer: [Clears throat] Quite a lot of the people that we've interviewed are older [J: Um hm] and quite a few of them have said in a funny way it's a blessing that you know it's allowed them to get their house in order, it's allowed them to do this, I think as a young person you don't think of it.

No it's, it's not **[I: Tell me]**, it's not a blessing. You know it's not something that I think now I feel so differently about life because I've had this you know horrible experience which has changed me for the better, like that's not the case. If I could take it away tomorrow I would. If I could change one thing [becomes emotional] about my life it would be that I wouldn't be going through this, but I know I can't, but I feel angry that I'm young and you know I felt like I was so able and had the whole world at my feet.

And now I don't have that and I have, I guess I have like a ditch that I'm trying not to fall down. I think what makes me upset the most is

the impact [becomes emotional] that it has on the people that you love. Being ill, the impact that it has on your family and I try so hard to be positive for, for my whole family and for my parents, my siblings, and everyone, but actually it's really unfair and I think it's heartbreaking because they know that they, they can't fix it for me.

I think they find that really hard, cos I think as a parent you probably, you probably just as a parent you probably just want to protect your children, and unfortunately this whole situation is out of our control, and they can only do so much. And I think it's really hard to see you know it's not only me that it affects being ill but it's my whole family.

Death and dying

I can't explain to you how hard it is to feel like your life is going to be over before it's begun [I: Mm]. That's really unfair. I definitely fe-, know that I'm going to keep fighting, but I know that eventually I won't win, but if I admit that I'm not going to win then I'll lose sooner.

Interviewer: Yeah. That's quite scary that admission isn't it?

Yeah, because ultimately we all know that I'm living on borrowed time. Like that's pretty hard to comprehend but we all know it's true.

Interviewer: Breathe deeply.

[Breathes deeply] Mm yeah that's, that's a real tough one. When I'm less well I guess I'll end up going and living at home with my mum back in Northampton and I don't really want to do that anytime soon or by choice because to me that's the beginning of sort of a downward spiral. [I: Um hm] I think once I've done that, whenever that might be, it could be three months, it could be three years from now I kind of know that that's the beginning of the end. So I'm going to stay you know standing on my two feet independently for as long as I can I guess.

Interviewer: Do you feel like you're on a downward spiral or do you not want to go there?

I think ultimately, I think ultimately I, we all know I'm on a downward spiral. We all know that every day that goes by that I'm really well it's a day closer to the end, and that will most likely be you know a lot sooner than other people my age, and you know I'll know the reason why, and I think that's really hard, because I don't quite accept it yet. I think in some ways I accept that dying is inevitable and I know it is for everyone, but I accept that I will die young.

What I find really hard generally is, is knowing that I don't have a future, realistically; is knowing that that's been taken away from me. I feel a bit, I guess I feel kind of robbed of that, and I'm going to be thirty next year, but realistically am I going to make thirty? I can't answer that.

Interviewer: Does it scare you?

Yeah definitely.

Interviewer: Does it?

I don't think it scares me, I don't think I'm scared of dying. I think I'm scared for my family about what they would go through if I wasn't there. I think that's actually harder than me thinking about, you know I don't, I'm not scared of dying, I'm scared for them. In order to be I guess at peace with the fact that you're going to die you have to kind of believe that there is something positive beyond this world, and you know I'm not religious. I don't go to church but I have to believe there's something else beyond this life because I don't want this to be it.

Interviewer: Mm. Have you found what the something is or do you look, or are you just like?

No. I um, I think I'll know when I find it, I'll get there. I don't know what it is. [Laughter]