

My name's Louise and I was diagnosed with stage four breast cancer when I was forty-four. I have four beautiful children, and I just want to see them through childhood, so like I'm going to fight like, like [laughs] mad.

Diagnosis

For breast cancer they say this is incurable but it is treatable, which basically means they can't cure it, but they can try and extend the life that you have and give you some quality of life. They said this is incurable but we can treat it. I deliberately didn't ask them how long because I knew that they, I could die in six months, that maybe I'll be one who lives a few years and they won't know until they try the treatments. So I thought I'm not even going to ask them because the most we ask is, my husband wanted to was would I ever make ten years and the oncologist said well that would be remarkable, and then he said how about five. And then he sa-, the oncologist said that would be very good, and so I know that at the time the, the general prognosis was about two, two and a bit years.

I didn't know enough about what it would mean, so I didn't know does that mean I'm going to die in a week. Does it mean I'm going to, you know what does it mean? Um how I'm going to tell people? Oh how can I have done that to my children? Um it was just absolute feeling of just horrible cold terror. If you're told you've got two years you, I think your body just prepares for death.

And I'm absolutely certain that there's a, there's something that kind of clicks in that just thinks okay and maybe there's some acceptance of it. And I thought if I'm given that information then maybe I will just live out what I'm told, whereas if I don't know then I won't ever be restrained by that. And so I prefer not to know because I, I believe that I'll, as long as I believe I can live then I can push the boat out.

You know it definitely isn't good. You know it was about as bad as it gets really if it goes into your liver. I know it can then get even worse but it's pretty damn bad. Um I just excel generally in things and I definitely did in this [laughs] in this instance.

Telling the children

I said something like um well I've got some bad news. I probably did say I've got some bad news and I said um you know mum's cancer's come back, and I don't, I definitely didn't say um that I, and I'm going to die from it and I, I have never said that directly to them. But I

haven't lied to them. Um I say, I say it ca-, if they can't do this then it can kill you and if your liver doesn't work then you know that means you know you can die but I haven't said I will die.

I'll tell you a conversation I had with Ned. He's the youngest, and I wanted to know if he had thought about me dying. I've never said to him directly um mummy is probably going to die. So then I said, have you ever thought about me dying? And he went kind of quiet, and he looked out the window and he looked around, like he was embarrassed that, and then I knew that he had.

And then, and I said it's okay if you have, and he said yes I, you know he goes yes I have, and I said and, and what does that make you feel, what's happens cos you know what if I do die. I said I'm tr-, going to try not to, I'm trying really hard not to, but what if I do. And he went um, he went well tsk you know I, I think I might, I might cry you know a lot for ma-, maybe an hour [laughs]. So then I went AN HOUR? You'd only cry for an hour?

And uh and then it was you know just like it broke, I felt so relieved that he, even though we'd not talked about it directly in that way, that he was under no illusion that I might die. Everyone knows. He, he, the whole community know I've got advanced cancer. Um you know the whole family know. So I felt so much better that we were talking and that he knew that, but that he knew I was fighting, and that's what I say with all of them individually, and I manage to, I manage to impart things that I probably wouldn't impart, like with William. He didn't know whether to take a, a maths, an extra maths class cos he was scared that he was going to just not do very well.

And I, I said you know sweets you're going to fail in life. It's not going to always be you know but if you don't try then you, you're never going to get it anyway. I don't know, it was some meaningful imparting but it suddenly me-, feels so much more now because I think I've only got this small time. So how can I, without spending my entire time giving them lots of lessons on life, how can I kind of weave them in so it looks like I'm not being too deliberate.

But at the same time give them you know, tell them the things that I want to tell them all through their life.

Being positive

No I, I'm really positive most of the time, honestly I am. I don't want to die, but I honestly believe that I have been one of the luckiest people ever you know in the whole world, and so maybe I didn't get the whole full run that I might have, but I've done so much in my life and I'm so grateful. I'm so grateful I, this didn't happen before I had

children. I'm so grateful that I've seen them grow up, and I can almost see the adults that they'll be.

So we're very careful about the way that I just try and keep the, the, the kind of the mood in the house just a happy positive mood, and not one that's entirely devoted to what my particular, how I am today. So I just started searching survival stories cos I thought as long as I can just find one survival story then I have hope and if I have hope then you know so, you know I, I probably will die, I'm sure that I'm not going to be the one, but I might be and as long as I might be then I'm not lying when I tell the children. And uh I think that means that I want them to have in their head that they probably won't have their mum around.

But I also want them to have just that little bit that goes but maybe I will, because otherwise they've like given up on me before I'm even dead.

Coping mechanisms - alternative treatments

They know that people with cancer like I have it die, and that I might die, and I possibly, probably will die, but I'm going to keep trying to work through treatments, and hope that this amazing one comes along just in time and that maybe I don't die quite so soon, and then as long as I've got the hope and they've got the hope it means that every day feels just a bit lighter.

No, I do spend a very, very long time researching alternative treatments and, and then going around the world [laughs]. I do, I go around the world and you know what, I would like to think that they are going to extend my life and they are extending the quality of my life and the length of it. I've got an infrared sauna upstairs, a little sort of tent with these lights that I go and sit under occasionally. I soak in Epsom salt baths. I drink lots of vegetable juices. I went vegan. I don't eat any sugar [laughs]. I don't have any alcohol. I take uh you know aspirin, suitcases of supplement, curcumin, that's turmeric.

In fact I'm much more healthier than I've probably [laughs] ever been. I crave Kettle crisps. I crave um, I crave croissants. I have the, a bit of me that thinks that probably it's inevitable and but then there's another bit of me that goes but no I'm, you know I'm going to keep, I'm going to just keep going just in case, because I might just catch that, that new treatment that comes out.

I think that as long as it's not going to do you any harm and it might do you some good then why on earth not, and if you're fighting for your life you do bloody anything. I don't believe that I'll live a normal length of life, but I do believe that I am going to be able to extend it with these treatments. I absolutely know, there were some amazing

responses that people are achieving, but they just come at a huge cost. And as long as I've got my children I will, I will fight for those treatments.

Coping mechanisms - work

I love my work and when I go to work now I, it reminds me that even though I'm, might be dying I still have some useful things to say, and it takes my mind. I don't spend every single day thinking, every moment of the day thinking about what's going on. I suddenly realise I've just been sitting in a normal meeting, and people have been treating me just normally and they haven't been relating to me as someone who's ill.

They've just been relating to Louise again and it was a bit strange when I had to go first when I lost my hair last time I had to go in with a wig, and I know that people originally thought uh, uh and it must have been difficult, I would have thought that oh my God what is she doing at work? What would you do? Cos everyone, you know everyone's thinking what would I do if I found that? Uh would I really go back to work? And I'm sure there were people thinking that.

But now I go every day and everyone treats me completely normally and I feel normal and I want to be normal. I don't want to be the person who's you know got the, the, they're very kind to me as well [laughs] but uh so it's also helped me feel normal, but it's also something I really love and I, I couldn't imagine not having my phone and quick checking my emails and sending something back, and sorting something out, and if I didn't have that I'd just think 'who am I?' you know what.

So it's been something that's been a major, major part of all of my life and in fact has remained an important part, even though I have cut my hours now and I can't be quite the person I was. That makes me upset sometimes. I can't race-, I did, I did just recently do a quick trip to Tanzania but [laughs] that was uh the first time in two years and I used to travel all the time prior to that. So I've had to change and, and I don't quite feel I'm the same person that I was, but I'm, you know I'm still there [laughs].

Intensity

All the things that you thought were just drudgery or dull you think how lucky I am that I'm still here to be cutting these potatoes [laughs] you know or to be walking around the supermarket [pause], Just to have this cup of tea, isn't this cup of tea delicious, and look at that little sun patch in the garden [laughs], and then looking at the sea

and thinking wow that's just been there forever and it's always going to be there and that gives me comfort.

And, and then just sort of placing my life in the whole length of the world and thinking you know what, I'm nothing really, or right um as in, I, I've had my children. I've been happy and hey I didn't maybe make it to eighty, but what would I have done at eighty anyway. And just because, uh so I even try and work through and I say why am I upset?

And I know I'm upset because of my children and my husband, but they, I know that they are going to be okay. Um I mean I, I'm working at it still and I want some more time to make sure that they, and I feel as if they've had enough of me. I feel I, my husband will miss me I know, but you know I say he's, he will have another chapter.

And um you know I'd far prefer to have had a, a lovely happy lucky life that I've had and die early than have had a long life with a miserable marriage and ill children.

Project management - making memories

Maybe there's someone looking after me and they just are saying come on Lou you've been given this chance. You've been given an opportunity. You haven't been run over by a bus, just pull your finger out and make your memories for your children and give them, you know do it now. And so now I feel it gives me a real strength. I really enjoy it. I feel really privileged that I've got the time to do that and I'm using this time now.

And I've like planned out, I've got, I've sort of planned out my what I want to do before I die, and it's not, you know it, it doesn't involve jumping out of you know aeroplanes or, it's about organising the photographs for the children because I'm the only one who ever knows where everything is. I'm going to knit them each a blanket and of course if you've got a project you can't die until your project is over. So four children, four blankets and a hopeless knitter means that I'll be working on that project [laughs] for a very long time.

I reckon that probably I am so slow that being realistic I don't think I'm going to get four blankets out. So I've now adapted it to two blankets of baby size, cos then I thought well I will think about my grandchildren. So I'm going to create really disgusting [laughs] blankets that all of the children will have to use for their grandchildren. They're all going to have to say my mother knitted this blanket for you, your grandmother. So then my grandchildren have a blanket as well.

You know I get to write them notes. I get to write them, I've got some, some uh postcards and I write little messages. So they've got a block of postcards so that they can just like pick one out and it just says things like if, we always do a sweepstake when it's uh the World Cup [becomes emotional] and that they still have to include a couple for me [laughs].

Project management - preparing the children

So Ned is the one who is the youngest. Ned is still very much a child, and with his older brothers and sisters leaving um as they grow older I, I just have been in terror of the idea of him without a mother um coming home from school to an empty house, and I, at a time for a boy, I don't know, he's thirteen now, I don't know how long I'll go on for, but certainly at a vulnerable time for a boy.

And so I've sent him to my sister's for a term, and my sister is, has got her own children and she lives in Singapore, and she's, she is a bit like me. I think she mothers like me. And my ambition is that he builds a much closer relationship with Cecilia, so that maybe if I don't make it that he could possibly go to school there, but it's one of those things I was afraid of and I feel like I've made just such the right decision to give him that life for when I'm not here.

Interviewer: Not a bit hard to see well how long have I got and I'm going to send my wee boy away but I think you've explained it.

I, there's a little bit of me that feels as if you know my need to prepare him for when I'm not here is greater than my need for him to have that time now with me.

Denial and hope

Interviewer: I'm going to ask you a really horrible, tough question

Yeah

Interviewer: But you're not in denial are you? You kind of know the reality of the situation. It's just your way of dealing with it.

Okay I know I'm not in denial. I know that I'm not going to live a normal life, a normal length of life, but I'm just pulling back my um what I think is an acceptable remainder length of life [laughs]. And, and I'm rea-, there is a bit of me that just, just believes and just hopes that maybe, maybe if I can just keep myself alive for, for that much longer that one of the new therapies that you hear, every day you hear about breakthroughs in science and it takes so long for it to come through into a therapy.

But what if I was able to survive and then be that generation where they just caught me and actually that gave me another two years or another two years. So I have to say it's not, I don't think that's denial. I think that's hope and that isn't denial. I know that sometimes people probably [laughs] think oh she's completely deluded and poor woman, you know just agree with her and say yes, yes of course, but I really, really do believe that as long as there's a little bit of hope no one really knows when they're going to die.

I didn't know when I was going to die, before and I still don't know when I'm going to die. I'm probably going to die soon, but I might not. I know it's a very small might, but you know as long as there's a might then you know I've just got to live every day and um hope that um hope that I will defy the odds.

What have you learned about life?

I've learned that I probably was being too, too fast, that I just wanted life so much from such a young age. Uh my cousin used to, there was a song and it was [sings] slow down you crazy child and she, he always used to say that reminds me of you Louise because I always, I did things. I did them early and I did them fast. I, I did them big and I had children. I didn't just have two, I had four and I got a job and then, and now it's like I've just been stopped [claps hands] in my tracks.

And do you know I, I think I'd still live the same again though, but I think probably it contributed. I'm actually quite strong, and I am quite brave, and I'm kind of proud of myself actually [laughs].

Death and dying

And I feel strong, but I feel as if if I didn't have my family I'd wonder if I would be so strong. I, I feel that I'm, I'm achieving m-, the end of life, um in a way that I would respect someone for doing, and every time I see the children happy and um our family just functioning as normally as possible I'm so proud of myself that we are managing to do this, um and not be a, you know dominated by the possible death of mum.

And I think I have accepted that I won't live my full life at all, and I'm trying to think what would I be happy with. Right now I'd be happy with next year. I had such a lovely summer with the kids. So I'm thinking if I could just have one year then I'd be happy. I might not have a year. At the moment it's progressing, and I've started a new treatment to try and get it down.

Interviewer: Here's a tricky question but do you think in a way the situation you're in is easier for you than it is for the people around you?

I, I think I find it harder, I, I think I find it harder. I know that it's hard for Rupert, [pause] um and is it fair to say that I find it harder. I think that he knows that he will have the children and that they will have such a job and so I think that they know that their togetherness [becomes emotional] yeah but just without me you know [cries].

I mean I'm a bit jealous [laughs]. You know I, I mean I don't ever feel, I don't feel angry, I just, it's just damn [laughs] you know damn. Yeah damn. I mean we always say you know if and when I die that they've just got to go on a great big holiday. You know they've always and, and they all go on a big holiday and I know that they will have, I know they'll laugh.

Interviewer: Is it sometimes a bit lonely?

Um you know it is lonely, it is lonely because in a way [pause] it's like there's a party [becomes emotional] and you've been told it's time to leave, and I don't want to leave the party [laughs]