

A Kind of Journey

Angela's Story

"I'm going to fight as much as I can fight in order to preserve my life for as long as I can."



My sister took it worse than I did. "Why couldn't it be me?" she said. "I wouldn't want it to be you, or anyone else because at the end of the day whatever kind of journey I have to go on I wouldn't want to push it onto anybody else" I said. Even though I am the younger sister I am the stronger one. I had to be her comforter. Don't worry I'm not going anywhere and God willing I will get through this, I had to say. We had to switch roles. My sister and me are very close. I think for her it was the initial shock of, oh no my sister's got cancer. It did shake her up. Even now she fusses over me but she said it has made her stronger. She says I have instilled strength in her. If I hadn't then maybe it would be hard to cope with myself and with my sister. I'm trying to show her that if she gets stressed out then she may end up in my predicament.

When I was diagnosed the doctor said I wasn't going to die. What do we do next? was my main thought. I was diagnosed in 2003. At the time I was having tests for my heart because I suffer with high blood pressure and I was getting palpitations. I remember having a bath and thinking that I was going to have to have a pacemaker. I'd not had an operation besides having caesarean section with my children. How am I going to cope? I was thinking. My daughter came into my room after I'd had a bath and I have always checked myself – I've always done it. "Mom, what are you doing that for?" she asked. I explained and while she was talking to me she said, "Mom, you've got a lump on your breast". I had been thinking about the pacemaker, but she was right you could actually see it and I could feel it.

She encouraged me to go to the doctor. I had to go and see the doctor anyway. My doctor was very good. "I'm going to get you checked out at the hospital" she said. The thought crossed my mind that this could be serious. However, what took away a lot of my fear was the thought of the pacemaker. I was so focused on that. I had the mammogram very quickly. I went with my mom.

I was struck by how many people were in the waiting room. All these people of all different ages diagnosed with cancer, and people kept coming up to my mom. "How are you coping?" they'd say. They were presuming it was her not me. "It's not me it's my daughter" she'd say.

When the doctor called me in I didn't even sit down. "Is it cancer?" I asked. He couldn't hide it he said, "I'm so sorry," and at that point I wanted to say, "it's alright" but then my thoughts switched

to my mom who was in reception and I began to wonder how I was going to tell her. So I asked how bad it was and if I was going to die. He said he wasn't sure and that I needed to have a biopsy. I just wanted to know yes or no, and I had to go back the next day. They said they weren't sure but that I might have to have a mastectomy.

I had to get a Macmillan nurse to tell my mom. She knew from my expression. I'd said I didn't want my mom to be in the room with me because I thought it would be too hard for her. My main concern at the time was for my mom because she'd lost my father and was still recovering from that. I had said to her before I went in that it could be cancer or it could be a cyst because a lot of people had said that. At the same time at the back of my mind I had to be prepared and get my head together. I asked my Macmillan nurse to explain to my mom because I didn't think I'd be able to use the words in the right order. I asked her to explain it for me. I remember my mom looking at me and me saying, "I need you to speak to my Macmillan nurse". My mom didn't say a word she just held my hand and squeezed it so I knew. "Don't worry if it's bad news I'm here" she said. When the nurse explained I didn't look at my mom because I thought that if I looked at her she might break down. That to me would have been hard, you know. "Are you alright?" I kept saying and she was saying to me "are you alright?" It can't be easy for you to hear your child has been diagnosed with cancer, which people generally associate with older people.

The nurse explained things but I couldn't take it all in. Later I had to ask my mom "did she say such and such, because I can't remember?" All that kept going through my mind at that point was that I was going to die and I said to my mom, "I have got my two daughters to look after". I said to the doctor I wanted to know and I said "I know you're not God but I just want to know what are my chances?" "Will she have to have chemo?" my mom was saying. It was that that really shook my mom. I remember the expression on her face.

About a week later (it was very quick) I had to go on chemo because they said the cancer had progressed. I had chemo before I actually had my operation to shrink the lump because it was a good size. It was still growing. So after I had my chemo I had a lumpectomy.

What helped me be strong was that from my first diagnosis I met people who were willing to explain. I was in my late thirties and from a black person's point of view there weren't many people who you could talk to and ask about their experience and what kind of things I could expect. I would like other people who perhaps are the same age group as me or ethnic background to know this is how I dealt with it. When I had my mastectomy I could imagine what I would look like but none of the books showed it from the perspective of a black or Asian person. That's how Kay came into it. She was a patient too and we became friends. I could explain to her what it was like having chemo and she could explain to me what it was like having reconstruction. At the moment I haven't had reconstruction.

I remember it was amazing being diagnosed because suddenly everywhere I looked seemed to be about breast cancer – there was that woman on Holby City. I remember her saying that for women who might fear having this operation this is how you'll look. She was the first person who I saw physically and I thought – it doesn't look that bad. I also thought, how am I going to look? My scar's going to look totally different to that because she's a different colour. On GMTV that particular week they explained how you look before and how you can look after. It gave me a bit

of peace of mind. It was very helpful.

In 2003 I had the chemo from July to the January. About March I went for my first surgery, that was the lumpectomy. The consultant said that because of my age he didn't want to do a mastectomy, but I ended up with a blood clot. I went through quite a rough time. My consultant was fantastic but the person who worked under her just didn't listen. I asked if he could tell me anything I should look out for so I could identify good or bad. I kept getting very dizzy. My drain seemed to be filling up with a lot of blood. It eased up but then it started getting kind of swollen et cetera. That gave me a bit of a problem so I got that done and then after that got the results back. They said it had progressed even further so therefore I would have to have the mastectomy. I chose to have that straight away. Two months after having the lumpectomy I was back in surgery having the mastectomy. They said that hopefully they had got everything.

The night before surgery I had a bath and I remember talking to my breast and saying "I'm going to miss you so much but it is something that has to be done and if it means saving my life it will have to be done".

I can have reconstruction if I want to but in a way I wish I could have had it while having the surgery, but that wasn't to be for me.

I think my biggest knock was when after I had my lumpectomy I had to go back to see my consultant for my results, and I'll never forget I was sitting in the room and I knew it was bad news. I suspected it because so many of them came into the room. "Why are so many people coming into this room?" I thought. There was my surgeon, my Macmillan nurse, and another nurse that I had been talking to. In all there were four people and I sensed they'd say that I would have to go down the mastectomy route. I started to rock because I was so nervous. I was wondering what was going on and I was a bit agitated. When they came in I got jittery. My mom rubbed my hands as though to say, you'll be all right.

My consultant knew I was a friendly kind of person who gets on with people but she could see what I was going through. "Just tell me what's going on!" I said and I started getting into a panic. "Why do you need so many people in this room? Why do you need so many people to tell me?" "You'll be alright. Come on, Angie, calm down now" my mom said. My head was spinning but I knew I did need to calm down because I knew that whatever it was she was going to tell me I wouldn't take it in if I didn't. It brought back memories of when I had my youngest daughter and I had to have an emergency Caesarean and I can remember just seeing all these people. So I thought – this is going to be bad news. As the consultant talked I had to look at my mom because I couldn't take it in and I wanted my mom to. It was reality and I knew that what she explained to me wasn't going to go away. I kept saying "am I going to lose my breast?" and my mom was asking if I'd need chemotherapy. The answer was yes, but I honestly can't remember a lot of it. "Right, what are we going to do and what will the treatment be like?" I began to think once I calmed down.

By the time I started on chemo I had peace of mind that I knew that they had done everything possible to prevent me from having a mastectomy and dealing with it that way. I could say, well they tried the lumpectomy and that couldn't stop what was happening now.

When I had my first course of chemo my nurse explained everything. If I was worried about anything she'd tell me the truth. I said I didn't want to be pampered. I said that if anything was going to hurt me to tell me so that I could prepare myself. I needed to come to terms with the experience and understand it so that I could deal with it.

The nurse explained to me that with the chemo my hair was going to go. She told me of other side effects too so from that first session I could prepare myself. I didn't want to wear the hospital wigs because they looked too bulky and didn't look natural so I had my own wigs made. They are caps and they consist of human hair. They made me feel more in control, better. I could have the styles that I wanted.

On my first course of chemo my mom came with me and my doctor organised for an ambulance to pick me up. "Do you need a wheelchair?" they would say approaching my mom.

I've always said I don't want people feeling sorry for me. As soon as the word cancer is mentioned I don't want them to think, poor Angie. I want them to think I am the same person. I have high blood pressure and I have to take medication for that, with cancer it's just the same. I have to have treatment.

The chemo went fine but I gained a lot of weight. I went from eleven stone to sixteen stone. That was the steroids. My doctor said that if I had not had that operation when I did I wouldn't have lived to see Christmas. I didn't know that at the time because I left it up to my doctor how to tell me and to judge the timing of that. She told me things, but not all at once. After my operation and after my chemo I was more focused. I just got on with it. That was my way of dealing with it, because of my family and my friends I couldn't think, well it should have been you. I thought God willing I've got a chance here. I'm going to fight as much as I can fight in order to preserve my life for as long as I can.

Some days having the chemo made me very tired. I had days when I was up and I was down. I don't know whether it was an adrenaline thing but most of my times were up. Last year though was a very bad year for me. I don't know whether the reality of what I had actually been through hit me. A lot of it was to do with my last operation. Physically and mentally I had to go inside myself to bring myself out of it because when I was diagnosed with cancer it didn't seem to affect me as much as when I had the operation – the symptoms and the emotions. I think also the medication; I was on morphine and that had a lot to do with bringing me down. I think it was just the fact of the reality – this is what my body has been through. Also financially it was difficult. Before being diagnosed I was working. I was planning to train to teach. I had just qualified as a chef and cake decorator and I wanted to go out into the community to give it back. That is not possible right now. Another thing was I found last year my daughter was diagnosed with diabetes at sixteen.

Financially, with state benefit, they give it you today and tomorrow they take it away from you and I found, therefore, I was having problems with my finances. If I had to go somewhere I would have to pay for taxis et cetera and I found that it hit me then and took me to a very dark place. I found that if you can cope with it they tend not to be there.

The Bridges Care Coordinator recommended the massage therapy that was absolutely the best.

“Do you know what, I’m just going to book it” my sister said to me one day. She booked a holiday in Turkey. That was absolutely amazing. Everything I’d been through all this time hit me – I was crying. I couldn’t eat, couldn’t sleep, I was snappy. The medication was affecting me. Also the menopause - I was having hot flushes. My body was aching and that made me very low. If other people said, “I’ve been through all of this and it hasn’t affected me” I’d have to think - really? I’ve met ladies in hospital who’ve been having breakdowns because they can’t cope with it. It hit me and when it did I felt relieved in a way. I can’t be high energy all the time.

God is on my side. My faith in God has got stronger and I’ve met amazing people. One woman had a double mastectomy and another had cancer through her body and she was like a skeleton. She was posh, and we would have a laugh and a joke. We’d talk and she’d tell me certain things. The nurses found it hard to talk to her because she’d say she didn’t want to talk. I remember saying I was going to have a makeover and I told her that when I did I would come and show her – you know, just to pick her up. “ Yes, I would like that” she said. I phoned up and went to the hospital and when I got to the ward the nurse asked me to come to the side. She had just passed away. She had twins, eighteen months old.

The other lady I met was when I went for my mastectomy. This lady was a teacher. I remember she was walking around and then as the days progressed she couldn’t get out of bed. We used to talk at night time. You’ve got to fight it we used to say to her. I heard her take her last breath. When I do have my low days I think of them. I know they would like to be in my position. I use that as my strength to pick myself back up.

I was at hospital last week and I met this gentleman. This lady sat next to me and I told her I’d come for a check-up and I said if you like I’ll explain what happened to me. In my family I say check yourself. I tell them what a mastectomy looks like. I find that people explained certain things and that made me feel comfortable. When I go to the hospital they sometimes ask if I will have a trainee. I say yeah because if they don’t learn we aren’t going to survive. I want to survive as long as I can. I have no qualms in explaining to other people. I explained to this lady’s husband, who was agitated, she will have to go through chemo. “Do you feel like you’re getting to that light at the end of the tunnel?” he said. “Do you know something, I try not to think about that tunnel I just concentrate on what is happening now” I replied.

Hopefully I will progress to the end of the tunnel but at this point in time I have come to my fifth year. If I dwell on the end of the tunnel it will start making me feel paranoid. His partner said to me that she felt that there was light at the end of the tunnel. Hopefully I am getting closer to getting there but I also have to be realistic and I know that it can come back. Therefore I have to think, don’t think about the light just concentrate on now. We could all walk outside and get knocked down by a bus. Positivity has got me to the point that I have got to now. I reached that low point. Now I go with the flow and I’ll deal with it in the best way I can.

People say to me, has it changed you? In some ways it has but I am still the same person I was. If anything it has made me a bit stronger. My friends say that I do too much for people rather than for myself. Sometimes now I also do things for me.

Finances aren't there. Being at my low point I thought, survive on what you've got. Why are you worried because if you're dead tomorrow they can't be paid. Last year I wouldn't have been able to talk to you like this. In certain ways it has made me stronger.

When I come out of this life there will be some one else in the same predicament and so by sharing my story I hope to help them.

In 2004 I had my second operation I didn't have to have chemo after that.

I did have a lot of problems when I was in hospital after my surgery. They thought they saw a shadow over my ovary but luckily enough it wasn't anything serious. It caused a lot of pain. I was in hospital for a month. The pain was horrific and it was worse than anything else. That's why I haven't been in for reconstruction.

During the chemo I drank a lot of water and tried to stay positive and also my cousin in London used to phone me up and send me CDs. That really helped. "If Mummy is by herself it doesn't mean I don't love you; I just need to be by myself" I would say to my daughters.

Regarding my children, my eldest is now nineteen and my youngest is fourteen. It was my eldest who saw the lump. I decided from the beginning I would tell them the truth and I waited to get all the information before I did that. My eldest went on the Internet. "Mummy, if you have to have chemo, it's not as bad as it used to be" she said.

I remember having my chemo. I had my hair in extension plaits. At the hospital they said, "Oh you've got such beautiful hair and you're going to lose it all". "When I come back again I'll come back different" I said. So when I went home I washed it and the one thing I didn't want was to lie down and it to come off on the pillow. As I tried to make plaits it began to fall out. My youngest daughter said, "I don't know how to tell you this, Mom, be prepared ... Your hair's coming out". It had started to come out at the root. "I don't want you to do it by yourself. So I'll feel better if I can help" she said. So I remember taking it out... I was completely bald then. "Come on you can help me wash it" I said to her and that was my way for her not to be scared.

My older daughter had been out and I remember going to the door and my younger daughter said, "be strong now, because Mom's lost all her hair". For about two hours she couldn't come into the room. Eventually she composed herself. I put a headscarf on. "I want to see what you look like because I want you to be able to walk around the house comfortable" she said. I made a promise that if I did lose my hair I wouldn't cut it. Having the wig on you're not going to be able to see it any way.

I have to give credit to the women who walk around without the scarves and a bald head. It's not a vanity thing from me. I just didn't feel comfortable except in my own house. With my youngest nephew I was careful because his parents died from cancer. He said to me "it breaks my heart". So I had a code. "Fix up, look sharp" he'd say, so therefore, I'd know to fix it. With my other nephew he was different. "What do you think about my new hairstyle?" I'd say to him and he'd go, "there you go again". But that was my way for them to feel comfortable around me. I didn't want them to tiptoe around me.

One day I had like a premonition just before I was diagnosed. What would I do if I had cancer? I thought. I was watching telly and the thought of cancer came into my head. My mom thinks it was a way I could be prepared.

I refuse to let it beat me. I am also realistic that there is a possibility it can come back, but we can get through it if we have to. I had an aunty who died from it. It gives me the strength to say, come on now, pick yourself up, brush yourself down and fight this. Some friends have distanced themselves. "Look, if I'm not feeling good on a particular day then I will just tell you" I've said.

I went on holiday. I wore a bikini. I had put on weight and I'd always been kind of slim but it was what was keeping me alive. I say don't feel sorry for yourself because I've seen the children and babies on the wards in hospital. They have to put them to sleep to give them the chemo. That makes me say to myself, I'm awake. It takes some things like that to take you out of yourself.