Series 3, Episode 3: Cancer as a taboo

Angie Greaves:

How do you cope with a cancer diagnosis when cancer is a taboo within your community?

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Angie: Hello, I'm Angie Greaves, and welcome to Talking Cancer, a podcast from Macmillan sponsored by our friends over at Boots, where I'll be meeting real people to have frank discussions about living with cancer. I'll also be speaking to Macmillan and Boots professionals who will be sharing their knowledge and advice to help anyone living with or affected by cancer to live life as fully as they can. In this episode, we're talking cancer with Iyna.

Iyna: I went to self examine and feel my breast and I felt quite a solid lump.

Angie: In January 2015, at the young age of 30, Iyna was diagnosed with stage 3 breast cancer and had to deal with this alongside the stigmas surrounding cancer in her community.

Iyna: Somebody said to my sister, during my treatment, "Tell Iyna to wear a black bra and the cancer will go away. Tell her not to have her chemo."

Angie: Today I'll be talking to either about her cancer experience and how since finishing her treatment in 2016, she's been on a mission to improve the understanding and awareness around cancer in South Asian communities.

Iyna: Nobody in this world should ever have to go through cancer alone, forget having to go through it with a burden of all of these things around you.

Angie: We'll also be speaking to Bina, Boots Macmillan Information Pharmacist, for some advice about dealing with a cancer diagnosis, and where to find support or people to talk to.

Bina: I think my message would be, never stop talking about how you're feeling. You need to make sure that you get the right help.

Angie: We're Macmillan and we're talking cancer. Hi, Iyna. thank you so much for joining me. First of all, can you tell us a bit about what your life was like before your diagnosis in 2015?

Iyna: Of course. Life before diagnosis was very different to what it is now. I was a 30-year-old who had just got a very, very new, exciting job working for Air France KLM as a HR business partner. I was at the time a mom to a four-year-old boy. I was a wife, a sister, one of the youngest girls in siblings of six children. It was busy, honestly.

Angie: What were your future plans looking like?

Iyna: I've always been a planner, something that's massively changed now, but I've always been a planner. Future plans really were about settling down and creating a

secured future for my son, progressing within my career, building a safer, better house for him. Everything was about having a better balance of life really.

Angie: I love the word balance. If you get balanced in most areas of your life, you can say you are content. Tell me a little bit more about your wider family. Have you got siblings? Are you a close-knit family?

Iyna: We are, yes. We see each other quite a lot. We're a very big family and there's six siblings. I am the second youngest out of all. It's three boys and three girls. My younger brother is around four years younger than me. We're very, very close as a family. Mom and Dad are always around. We see each other, I would say about at least every week. The girls definitely do with the kids. We're all married other than the younger one. We've all got children. We see each other every weekend.

Angie: I'm getting an image of a very close-knit family like you say in-laws, moms, dads, nieces, nephews, it sounds lovely, really does. At 30, you probably weren't expecting to face any serious health worries, especially not breast cancer. How did your diagnosis come about? Did you have specific symptoms?

Iyna: No, honestly. Like you said, it definitely wasn't something I was expecting, new job, new house, everything had just fall into place at the last part of 2014. I was told in around November time 2014 that I had an underactive thyroid. I saw that I started to slowly gain a little bit of weight and which pretty much all my life I've had quite a steady weight. It got to January and I made this commitment like most people do, new year's resolution. I am going to exercise, work out, and be good. I did my workout in an evening, must have been quite late, nine, ten o'clock by the time I'd finished. I literally just scratched the surface of my right breast at the bottom and I felt something quite solid on the surface of my skin. I then went to self examine and feel my breast and I felt quite a solid lump at the bottom part of my breast. It was so solid and big that it was literally like a hard ball that I was able to grab.

Angie: When you were given this diagnosis, it was stage 3, you were at stage 3, weren't you?

Iyna: Yes.

Angie: Who did you initially turn to for support at the time?

Iyna: My husband was with me throughout the whole time. When I got the diagnosis, I called my older sister. I think the only thing I remember saying to her was, "I've got cancer [unintelligible 00:05:41] how in the world am I going to tell mom." That's all I could think of. I don't think my thought process went any further ahead than that.

Angie: What treatment plan was put in place for you?

Iyna: On the day, my plan changed as time goes along, which I think many people who have had breast cancer going through that journey would know that sometimes it can change. I had chemotherapy, I had six rounds. I then was given the option that if I wanted to, I could go for lumpectomy because the tumor had actually shrunk quite a lot and chemo did what it needed to do. Then I had radiotherapy and actually, it was a day before my surgery to have a mastectomy, that I called up my oncologist and changed

my mind and said, I want a lumpectomy. I think he thought I had gone absolutely crazy or lost my mind. I thought about it for such a long time, and did loads of research around what does a mastectomy look like for your life? I'd read people's reviews online, I'd read well how people were feeling. I went on to different groups and did all of that and I just thought, okay, this might have been right for many other people and that's okay, there's no right or wrong way around it. It's what's right for you. For me, I just can't see myself being the person who's going to worry for the rest of her life and live in fear that it's going to come back. I would rather have a lumpectomy and keep my breasts. That's what I decided to do. I called the oncologist literally a night before my surgery and said, "Can we please just go for a lumpectomy?" He was amazing. He said, "You can blimming change your mind on the morning if you want to, Iyna. Of course, you can."

Angie: You say that your body responded quite positively to the chemotherapy? Did you think about losing your hair? How did you find that part of the treatment? Did you have a reaction in that area?

Iyna: Oh, goodness, yes. Chemo, I'll be honest, absolutely knocked me senseless. It did what it needed to do, which was shrink the tumor. As anybody who's had chemo, I've been around people who have chemo know, it's supposed to kill the cancer cells, but what it does is it kills everything inside of you, and that's exactly what it did. After my first treatment, after 10 days exactly, I went into the shower with a full set of hair and I came out with nothing. It was very, very traumatic. I have to say, the experience of losing my hair was hard. I really struggled with that to the point, I still vividly recall being in the shower in my parents house, literally screaming, crying, saying God just give me strength to go through this because I could just see my hair in chunks falling out into the water. I think that was the only time I ever saw myself without my hair. From that moment onwards, I kept a head cap on, and nobody saw me without my hair, not even my husband, and not even myself. I would cover the mirror with a towel before I went in for a shower. I would turn my face to the mirror when I changed my clothes. I even slept with it on, because I just couldn't bear to see myself like that, because it was a constant reminder of what my life had become.

Angie: That sound like it had a serious emotional impact on you, the loss of the hair?

Iyna: Yes, hugely.

Angie: As well as managing the impact of the diagnosis on you and your family, and we know you've got a very close-knit family, you also had to handle the reaction of being part of the South Asian community.

Iyna: Yes.

Angie: Give me an insight as to how this affected you.

Iyna: It's really interesting because I experienced a very strange balance with it all. Direct family, if I look at my immediate family, siblings, mom, and dad, was it affected directly within that circle? No. Actually, when we talk about the South Asian community, we talk about not just being your brothers and sisters, you talk about the whole community, where you value together friends, family, parents and their friends and their

families and so forth. The impact, I didn't realize how big it was at the time, because my family had really massively, without me realizing, actually protected me from a lot of it. The impact I realized was afterwards, and it was things that were said without realizing from those people what their impact was. Somebody actually said to my dad, that your daughter must have done something wrong in life and this is a punishment from God. My dad is a very religious man, he prays five times a day, he always has done. I recall him saying to me, which really has stuck with me for a very, very long, and I think it will stick with me for life, he said to me, "God is there to guide you through this journey, and to give you strength to pull through this journey. You still do your treatment, having your treatment doesn't mean you're forgetting what your faith is, that is there to guide you and give you strength. You don't listen to these people that you hear around you saying that to you." Somebody said to my sister during my treatment, "Tell Iyna to wear a black bra and the cancer will go away. Tell her not to have her chemo." Somebody else said to me, "Don't have your treatment, just pray. You need to have more faith rather than relying on conventional medication." A lot of people then came round and it was things like, "Stop smiling because you've got cancer, people are coming to see how you are, you need to look like you're unwell." I was like, "Well, I am unwell. How am I supposed to look like? I'm sad. I am a cancer patient." It was the whole idea of you have to look and play a certain part, otherwise, people will not believe you because if they walk away and you're smiling, they'll be like, "Oh, she's fine. She's smiling. There's nothing wrong with her. The family exaggerated."

Angie: Iyna, alongside the cultural traditional stigmas, you've got to go into chemo with everything that's happening with that. How did that affect you? How did that affect your mind?

Iyna: The journey is hard enough. First just being told you've been diagnosed, and then having to go through the journey and navigate through-- You have to gain a PhD when you get cancer. You've got to self-teach yourself overnight. To have to do all of that with family and then hear these, honestly, I think without realizing it, I think it knocked my confidence in how strong I was initially. I think I started to doubt that if I was going to actually make it, if I was going to survive at some point. At some point, I would lie there at night and think, "I'm actually not going to make it." I recall a few times lying in bed thinking, "What did I do? What have I actually done? I don't think I've ever intentionally gone out and deliberately hurt someone. What have I done?" I started to really question myself and all of these things. When you start to question yourself and doubt yourself, you lose a part of the strength that you still need.

Angie: Family traditions, cultural traditions, can create a source of comfort. Sometimes it does the opposite.

Iyna: Absolutely does.

Angie: How did you get through the not-so-positive side of these cultural traditions?

Iyna: I always said to people, everybody has a driver. Everybody has their why, what their reason is for why they wake up in the morning, for why they fight battles every day, for why they do what they do. For me, my reason was my son. I would see my four-year-old son every single day and I would look at his face and think, "I can't let him see

mommy give up. I can't be setting that as an example for my son for the rest of my life. If something is going to happen to me, I'm blimming well going to fight it right to the end, and I'm going to let my son see that I'm going to fight it to the end." The only way to do that was to mentally stay strong. That's what I did. I went into tunnel vision. I focused on me, I focused on my health, and I blocked everything else out, including social media. I did everything and blocked everything out. Interviewer: What positive outlook to have in the midst of the not-so-positive side of the cultural areas. With your family, standing by your side, even though they're part of the community, part of the South Asian community, your family standing by your side, your sisters, your brothers, your in-laws, and you find this strength just to really keep going for your son. Did your family find that they were on the fence having to push back a lot of these comments as well?

Interviewee: Like I said, a lot of these comments, I didn't actually hear during my treatment because my family or my sisters hadn't actually told me. I found them out after they finished and it's because they were protecting me from this. I remember speaking to my mom through my treatment once when people came around to see me, extended family, friends, and I think once or twice, my dad's friends came around to see. I do always say, the reason why they've come around is not to poke and be nosy. They're actually coming because again, culturally, we want to be there for you and your family because your daughter's going through something. They're also coming from a place of love and care and respect, but I wasn't ready for that. I didn't want to feel like a showpiece sitting there, having to behave and be a certain way. I just wanted to do my journey my way. I spoke to my mom and said, "Mom, I can't do this. I can't have people coming to see me all the time and me just sitting there. I don't have the strength to do this." I absolutely love my mom for this. She's always been this person who will question and fight back in the community for what her kids want. She went and said to my dad, "Today will be the last time somebody walks into this house, who's not close family that my daughter does not want to see, into the house until her treatment's ended." Nobody ever did come after that.

Angie: Your mother sounds like a very strong woman.

Iyna: She's amazing because she's always put her kids first. Despite the challenges, it can be coming from a community that can be very, very heavy on influence and expectations.

Angie: Just veering off slightly. I once watched a film that said the man is the head of the household, but the mother is the neck and she turns the head in any direction. That sounds like your mom. [chuckles]

Iyna: Absolutely. [chuckles]

Angie: Now, look, I know you're not speaking on behalf of the entire South Asian community, you're speaking out of your experience. At a time like this, here is an opportunity for you to use the platform, just to say how you think in moving forward, people can change. I'm getting the impression that a lot of the statements are coming from maybe elders of your community.

Iyna: Honestly, interestingly, it actually wasn't just elderly people. I had a friend of a friend actually say to me, when I was speaking to my eldest brother, who's now 44, about my breast surgery, when I was deciding if I should go for a lumpectomy. She actually said to me, and who was my age at the time, so 30. She said to me, "How can you speak to your brother about a boob job?" That was a question I got. I said, "Excuse me. I'm not speaking to my brother about a boob job. I'm speaking to my brother about my surgery, because of breast cancer. It's a very different conversation." She said, I could never ever speak to my brother about my boobs. I said, "Well, he's comforting his sister to make sure she's okay." The only way, honestly, I see things changing and it is possible, change is always possible, people just need to do it, change comes from yourself, is people being more open about the fact that they have gone through a journey. To be open about their experience. To open up the conversations that we as South Asian women or men, do also get cancer. It does impact us as well. The more people that share it will get rid of that stigma, that taboo that sits within the community so there'll be more support, there'll be more places for people to seek support without having to go through it alone.

Angie: Iyna, you've come through the other side, you're in remission. Were there any times that you thought about some of the comments that were made on a traditional level, you must have done something wrong, wear a black bra, don't smile? Did you ever think about those once you'd prayed and had your treatment and were cancer-free?

Iyna: In 2018, I think it was, I'd gone on to Victoria Derbyshire Show to talk about breast cancer, my journey within it, and the impact of it in the South Asian community. So many women contacted me, they must have searched me on Facebook. Some of the things I heard from other South Asian women was, a lady had told me her children were taken away from her because the husband said that their daughters wouldn't get married if people in the community found out that their mom had breast cancer. Another said she had to hide the diagnosis from everybody because nobody was allowed to know she had breast cancer. Another one had to hide that it was breast cancer and had to say it was something else, another form because saying the word breast was not appropriate for her to say. Actually, I know a few women through the support groups I do as well, where their husbands left them in the middle of the treatment plan because they said, "You're not the woman I married. You don't look the way you look anymore. It's not my job as a man to look after you. You are supposed to be looking after the household." All of these things, alongside what I heard through my treatment, I would say probably was the biggest driver for me to do what I'm doing now because nobody in this world should ever have to go through cancer alone. Forget having to go through it with a burden of all of these things around you.

Angie: Focus more on the feelings and the emotions as opposed to the traditions. It's amazing that you want to use your experience and channel positivity into your community. Can you tell me some of the things that you intend to do or that you are doing to create this change?

Iyna: I really do see it and it sounds crazy, and a lot of people think I'm a bit mad, but I really do see cancer as some form of a gift that's been given actually because it's

changed my life. I'm trying to, I guess, share that gift, that present with other people. The way I'm at the moment doing it is in quite a few different forms. The two key things, I would say I'm focusing on is one is education around breast cancer and selfexamination. Breast, generally, is very sexualized. People don't want to talk about it. When you are within the South Asian community, you are basically brought up in that way. To the extent that when you are changing your clothes for example in a changing room at school with just girls, you will pull one arm in and then the other then a t-shirt will hang over your chest and then you'll put the other one on. You're constantly trying to cover yourself. You don't talk about bodies. Then if you add in the complex area of religion and into it for some religions within the South Asian community religiously you're not allowed to show your body. I'm trying to open up the conversations of why you should self-examine the importance of it, how you can do it in the comfort of your own home in privacy. It's still important to look after yourself and give yourself that time. The campaign that recently just launched is taking the number two taking two for me. Take two minutes out for yourself to self-examine because it could save your life. If you are not well and you are not around, how are you going to care for the people you love and the people that rely on you as well? That's one part of it. The second is something that I'm massively passionate about which has been slightly harder to push through and I'll be honest is changing the face of breast cancer and it being more modest. The campaigns, the adverts, the flyers, the posts that you see on social media seeing topless or women in lingerie on campaigns is normal for breast cancer. It's not wrong. I'm not saying it's wrong at all but that does not resonate or align with everybody. If we want for campaigns to make a real difference in women's lives and for a community that gets diagnosed at a very late stage because they're not going out and seeking support, then we really need to change the way we do these campaigns. Why do I have to be topless in order to talk about having breast cancer? Why can I not have a campaign that has a woman with clothes on, who looks like me so that I can take that flyer to my daughter without worrying about the cultural barriers that I'm brought up with? Why can't I do that? I'm trying to create a campaign and flyers that can go into mosques, into Gurdwaras where Sikhs pray, into Hindu temples, into school changing rooms, into workplace toilets. That will be modest flyers that can resonate with older women maybe who are not okay with nudity. With youngsters with South Asian women, with people, with cultural barriers with kids.

Angie: You're definitely a light amongst women. Anyway young married women with little kids but definitely in the South Asian Community as well. how's life been since you finished your treatment. Iyna: A rollercoaster is probably the right way. There's been some incredible highs and there has been some lows but that is life post-cancer, I would say. The outside of me looks the same but the inside of me is completely changed. I'm a different person. I really am. I wake up every single damn morning being grateful for opening my eyes. I think my husband absolutely loves the new me because we don't argue. We don't fuss over little things. [laughter]

Iyna: Life is too short for that so he's loving the new me. I keep saying the word balance but I'm absolutely loving the balance I have in life. At the moment I have my charity that I'm doing that I love. I can give time to my son. I have family. I go out, I eat, I shop, I go

crazy and I can do all that and still make a difference to people. Angie: I thank you so much for joining me. Thank you.

Iyna: Thank you so much for your time.

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Angie: Joining me now is Bina Mehta who is a Boots Pharmacist advanced practitioner. Bina, welcome to the podcast. Can you tell us a little bit about your role?

Bina Mehta: I'm a Boots Macmillan Information Pharmacist as well. What that means is that Boots Macmillan Information Pharmacists have received specialized training so they can see patients who have received cancer diagnosis or their loved ones and help them with a range of different queries. They could be on the test that they're receiving, the medications that they're receiving, any side effects from the medicines and managing them or they could be something to do with signposting them to local communities or any emotional financial, or social help that they may require. You can find a Boots Macmillan Information Pharmacist across all our stores in the country.

Angie: Bina in this episode we were talking about when cancer is a taboo within the community that you're a part of. I just want to know is this something that you hear about in your role?

Bina: We do hear about this every now and then the fact that it is a taboo, it means that people they're not openly talking about it. We do know that this is a big problem in some of the communities that we live in that the actual disease itself and trying to get better from it is put at the back. What other people are going to think about you having had this diagnosis or their perception of the disease, it kind of like takes over in that person's mind.

Angie: Bina when somebody from the community that Iyna experiences problems, how do you verbally deal with this? Some of Iyna's experiences, they were just heartbreaking

Bina: For me to hear or read about such stories they are so heartbreaking that such cultural beliefs and customs do not allow people to open up and talk about their symptoms. If a person came into my pharmacy and spoke to me about it, about the way that they were spoken to post their diagnosis, I think my message would be like never stop talking about how you're feeling and you need to make sure that you get the right help. If you feel that you are unable to speak to your family about it or your close friends or in the community that you are in, Macmillan have something really wonderful which is Macmillan online community. You can keep your identity anonymous in this as well because the whole aim and objective of you being part of this community is for you to have that space so that you can speak openly about it. Not only does this community have people who are going through similar phases in their lives, they all join this

community and they're like bounce off tips with each other. I would navigate with them through the Macmillan site and I would show them how to create an account and go onto this wonderful online community facility that's there.

Angie: How can people provide better information to their communities to help avoid experiences like Iyna's?

Bina: We need to make these communities realize that if a person has a diagnosis and they're unable to speak about it openly because of how that information may be received or perceived within their community, this is going to affect the mental health as well. I think there is room for work that needs to be done from a primary care point of view where we need people trying to get these communities together to allow the person to talk openly about it without sharing your so-called misconceptions and the way the disease is perceived traditionally and culturally in their particular background.

Angie: Then, of course, Bina there's the mental toll of receiving comments that aren't too positive. What support and advice would you give or recommend to anyone who's struggling with their mental health at the time of diagnosis and also through treatment?

Bina: Yes, it's really, really important to make sure that we're looking after our mental health whether we are not well or whether we are well because that's just something that's really important and mentally you have to be really, really fit. If someone came into my pharmacy and spoke to me about how they're feeling and that mentally they don't feel so great, then I would encourage them to keep on talking because benefits of talking about how you're feeling takes off that weight off your shoulders and that weight off your chest. I would also say to make an appointment with your GP just to be assessed because it's so important that the mental side of it is looked after.

Angie: Bina thank you so much.

Bina: Thank you so much Angie for having me. Angie: That was so powerful to hear Iyna's experience massive thanks to Iyna for sharing her story and to Bina for her words of advice. Now, for more information about what we've talked about in this episode and for more information about how to donate, please visit our website. www.macmillan.org.uk/podcast. I'm Angie Greaves. Talking Cancer is a Macmillan cancer support podcast.

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