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Speaker 1 ([00:05](#)):

A diagnosis of breast cancer can cause a life changing ripple effect of impact affecting those. We love the most and those upon whom we lean for comfort and strength in the most challenging of times, my name is Ashley Hurley and I'm the CEO of breast cancer Ireland. And you're listening to more than a lump, a podcast that talks openly and honestly, to a selection of guests about their very personal connection to breast cancer, be it through their career choice, their own firsthand experience of the disease, or through sharing the experience of close family members. My conversations will center on how breast cancer has informed their perspective on life, love, family health, their goals, and indeed their aspirations. Although each story is utterly unique. The one common thread that runs through each one is that breast cancer is more than a lump.

Speaker 1 ([01:00](#)):

In today's episode, we speak to a breast cancer survivor whose initial symptoms of breast cancer were more than a lump when Theresa Costlow at 36 years of age was examined by her consultant. It was an orange pill like rash on her breast. That was the one telltale sign of the disease. I chatted, there's out how being diagnosed with breast cancer has utterly changed the direction of her life and how her involvement with breast cancer Ireland as a patient ambassador, helping to raise vital funds to support pioneering research has, and is continuing to make a difference for women and men diagnosed Theresa then turns the tables and asks me some questions on what's coming up for breast cancer Ireland over the summer and into the future in terms of our outreach programs, the support of the 100 K challenge organized by Nile Carol and his wife, Cara, and the plans for the great pink run coming back after two years as a virtual event and have further investment into research and clinical trials will change the landscape of the disease in the future Theresa. You're very welcome to the final episode of season, one of more than a lump podcast. It's so lovely to see you and looking forward to our chat. I mentioned in our intro that one of your early signs of breast cancer was not a lump. Could you take us back to that day in 2013, your son I know was only just four years of age, you were fit and going to the gym regularly. What brought you to that first consultation?

Speaker 2 ([02:17](#)):

Well, for about a year before I was diagnosed with breast cancer, I, I had been kind of sick on and off with, um, constant sinus infections and I was just ne never getting well from them. Um, I kind of wasn't bouncing back and I was really, really tired a lot of the time. And, um, by chance I did actually find a lump in the shower, but when I went to my GP, he wasn't concerned. He said, you know, it's, it's probably a cyst, but I will err on the side of caution and, um, refer you onto St. James' hospital. So when I went into St James' hospital, um, my consultant asked me to raise my arms above my head and I had severe indentation and orange peel. So, you know, the lump, my GP wasn't worried about, but what I missed was a really, really huge telltale sign, which was the orange peel and the indentation and the indentation was really severe when they examined me, um, physically, uh, they found three tumors. Oh. So there was, there was quite a lot going on there and because I guess I was 36 and living a carefree lifestyle and, you know, thinking I was invincible. Um, I never took ownership of my breast health, so I never knew what my own normal was. Mm.

Speaker 1 ([03:44](#)):

And tell me about the treatment that you, you had to undertake.

Speaker 2 ([03:49](#)):

Yeah. So the treatment, it was, it, it all happened very quick. It was a where I went. Um, I was having chemotherapy within two weeks of being diagnosed. Um, I had a mix of chemotherapy, so I had four sessions of AC and four sessions of Taxol. Uh, there wasn't time for things like getting my eggs frozen or to think about having other children or making preparation because I, my cancer had a personality. It was kind of on the move. So they wanted to get me in to get me treated and save my life as quick as possible. Mm-hmm <affirmative> so, um, I did my, uh, 16 weeks of chemotherapy. Um, that brought me up to Christmas. I was diagnosed my AC actually, uh, my first chemotherapy, uh, treatment was the day after my son's birthday. Oh. So it was a really, it's a, it's an emotional thing being, um, diagnosed with breast cancer. But I was sitting there the night before I was due to going to chemo. I didn't know what was lay ahead of me. I didn't know if I was gonna be around in a couple of years or anything. And I looked at my child and he was a newborn a few years back and I was holding him my arms. And a few years later I was going in to have my life saved. Yeah.

Speaker 1 ([05:06](#)):

And how did you, and at what stage did you talk to Reese about what you were going through? Cause I find lots of women, younger women with younger children. It's a really difficult topic.

Speaker 2 ([05:19](#)):

Well, I was a single mom at the time, so it was me and Reese and he knew there was something wrong. I'd said to him, look at mom. Isn't very well, but I, I tried to kind of brush over and not give him loads of details, but it was, he, he, he knew there was a difference. My mom and dad were picking up the slack a lot at the time. Like we, with chemo, you can be very tired. And, um, I was afraid I was living, um, a bit away from my parents. So I was afraid if I got dizzy or faint at the age he was at, you know, so after I'd have my chemotherapy, my mom and dad would take them. So that was, that was a change in his routine. So he knew something was up with, I guess he didn't know the severity of it.

Speaker 2 ([06:02](#)):

It was kind of more when I finished my chemo treatment that I, I talked to him more about, I kind of wanted to get that under the belt, but he did actually discover that, um, I lost my hair himself cause I used to be wearing my wig all the time so that he wouldn't know. And one day he put his little hand up the wig and said, ma I know you have no hair <laugh> and he goes, and I still love you. Yeah. So, uh, he nearly, he nearly told me what was going on. But yeah, it, the thing with children is I would say, be very honest with him. I, I made a mistake. I, I probably wasn't as honest as I should have been with him cuz I was trying to protect him and I probably didn't want to face up to the reality of what was happening in my life anyway.

Speaker 2 ([06:42](#)):

Mm-hmm <affirmative> uh, I, you know, I always thought I was invincible and immortal and you know, I, I went for an appointment and held my arms over my head and I was, I realized very quickly, that's not the way life works. So I was so busy trying to protect him. Probably I would, I would've been more open with him, I think about if I had more time over again and please God, I don't. But um, you know, you kind of have to be honest with kids age appropriate age appropriately. Um, because he, he had a diff cause when we spoke about it later, he said, mom, I thought there was something going on with your head.

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And I was so afraid, you know? Yeah. He, he just thought was gonna keep coming back and back and back and back. So it, it was probably the way I, you know, dealt fit it.

Speaker 1 ([07:27](#)):

And I have to say, Reese now is like another amazing little ambassador for breast cancer Ireland. He's at every event that we host, whether it's great pink run with you running on running the, the route or whether it's like, I mean his communion, confirmation money given to breast cancer Ireland. I mean he's an absolute star.

Speaker 2 ([07:44](#)):

Yeah. And he, I, I think he's just very aware now and he is, you know, he's very in tune, which I think is good. He's 14 now. Yeah. So he he's, he's getting older. So it's, you know, he, and he talks about things real openly. So, um, that's what I'd like kind of, you know, all schools, you know, when they get to that age to be able to talk more openly about stuff like breast cancer.

Speaker 1 ([08:07](#)):

Yeah. And I, and I think even coming on from that, I remember your passion was online. Facebook was very much, you know, to the four at the time now Instagram has taken over, but you are very, very passionate about wanting to be there because so many people had contacted you when they realized you at a very young age had had breast cancer and you wanted to have a platform for them to be able to chat. And you set up breast friends.

Speaker 2 ([08:30](#)):

Yeah. Well like probably part to the reason why I, I wasn't checking myself was because, um, a, I thought it won't ever happen to me. Would B I thought breast cancer was, uh, an illness that only affected all their ladies mm-hmm <affirmative> so, you know, I wasn't aware and I think breast cancer can be a very lonely illness, I suppose when we go through anything, it can be lonely. We, we face things on our own because only us know what's going on in our heads. So, um, you know, I found it lonely at times and I, I kind of struggled to find somebody who I could identify with or who I could ask. You know, how do you feel about getting your head head shaped? Can you use time, you know, thing, or like, are you afraid you're not gonna be here in five years?

Speaker 2 ([09:16](#)):

And I always remember before I went in for chemo, I, I didn't know what was gonna happen with chemo. And I thought I was just gonna shrivel up and disappear. And one of my friends, uh, sat with me and she, she was like, Kylie, Kylie had breast cancer. Yeah. And she was showing me pictures of Kylie Minno and how she bounced back. And I was like, well, and that kind of gave me comfort, but then I thought, geez, I wouldn't mind talking to Kylie. Minno now picking up the phone and asking her like, you know, how's her feeling like, and you know, is she embarrassed or is she self-conscious I couldn't do that. But I know I'm just an ordinary girl, like, you know, who anybody can get in contact with. And that kind of spurred me on to set up best friends, because to sit with people and to reach out to people who are, you know, similar age or, you know, to find somebody who, if something, to come with somebody who you can identify with, even if they're not the same age as you is very powerful mm-hmm <affirmative> and can be very helpful when you're going through this party, your life.

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Speaker 2 ([10:24](#)):

So, you know, I met other girls along the way, who are in a similar age category and we, uh, drew great strength from each other. And we asked the questions that we probably weren't gonna sit in with a doctor and ask either and you know, or, or we probably confide the things in each other that we weren't gonna confide with our moms or our dads, or because there is that ripple effect. And you often mention it with breast cancer. It's not just a person who is diagnosed. It just ripples through the whole family. You know, you have children who are worried about their parents. If parents are worried about their children. Yeah. You, you know, everybody's affected, you know, you have friends, I get people contacting me asking me, how will I be there for the person who I love, who's going through breast cancer and breast friends.

Speaker 2 ([11:13](#)):

Um, I guess it's a place where I started off, um, sharing my journey and people followed. And then I always wanted it to be really open that people could message me if they needed support and I'd meet up with people for coffee and I'd ring them if they needed a chat and it, it just started to grow. And, um, I know Instagram has kind of taken over mm-hmm <affirmative> and social media, but I kind of stuck with Facebook with breast friends, because within Facebook, there's the function to have your private groups. Yeah. And so I have a public breast friends page where anybody can read anything, but then I have a private group there's over 2000 members and that's where a huge amount of support becomes alive. It's you have people who, one day they might be looking for support and the next day they're the ones with all the answers. Yeah. And, you know, they start out people, I've seen people start out with their journey, so afraid, so scared and so alone. And a year later I see them and they're a rock for other people on the page. Yeah. And it's, it's

Speaker 1 ([12:20](#)):

Comes

Speaker 2 ([12:20](#)):

Full circle. It's magical. Yeah. And it's it's, and, and with people with all stages of breast cancer as well, and, you know, things that people are probably, some people are shy about asking doctors are in, in Ireland. I think we're terrible. We think we're wasting everybody's time or we're, you know, oh, I don't wanna make a fuss. So sometimes people reach out to people who they know who've gone through us, that experience. And that's where breast friends comes in. And I, I promise, I always said, if, if I ever get better and I get over this, I'm going to, I'm gonna help as many people as I can. And I never want people to lie in a bed on their own. So scared and feeling like they have nobody through this and that's best friends. Like, I, I won't let anybody go through it. And I'm so accessible. If people message me. If people want to meet me for a coffee, I will be organizing monthly coffees. Now that life is back on the go again. Mm-hmm <affirmative> and it's just to give, give back mm-hmm <affirmative> and to make sure people have a, probably a little different experience,

Speaker 1 ([13:29](#)):

You know, and a safe place to have a chat with people who have either been through or are going through the same thing, which is amazing. It's a fantastic support service to offer. And I suppose that brings me on to the whole education and awareness piece. And now you are a counselor, um, and you are very much passionate about that, you know, the education and awareness program, something like

what we do on a complimentary basis in the communities, but you wanna take it another step further and actually have it, um, included in the curriculum in secondary schools.

Speaker 2 ([13:59](#)):

Yeah, absolutely. Um, look at my life totally changed after I had breast cancer and I was reset and set on a different path. And that included where I live my relationships, um, and my career mm-hmm <affirmative> so, um, yeah, I've I became a local counselor. Um, and with that, um, I began to advocate for, um, changes in screening also, but also the education piece, um, with younger girls, because I definitely never checked myself and I wanted, I, I, I think it's really important to break the, to the taboo about checking yourself and knowing your own normal and, you know, for kids to be educated about taking ownership of their own health mm-hmm <affirmative>. And so from an early age, if girls are checking their breasts and downloading the breast cancer early up yeah. Which is, is amazing for, uh, the monthly reminders. And there's, you know, there's the tutorial on it as well. But, you know, if people are taking ownership from a young age, they know their own normal. So, so far in advance that when something changes or there is an abnormality, you know, they, they knows it quicker. Mm-hmm <affirmative>, they don't go like me. Like I was nearly missing a quarter of a breast before I, I ended up with my consultant, you know? Yeah.

Speaker 1 ([15:26](#)):

Yeah. And I suppose then for our listeners, could you take us through sort of your time as a breast cancer, Ireland ambassador, this was people often wonder and they say, but what do they do as, as ambassadors, breast cancer Ireland, you've been very, very active, whether it's, you know, going and speaking on our behalf and speaking as part of talks that we give to communities, to companies, to school groups, to population in general. Um, can you talk, talk us through about that?

Speaker 2 ([15:53](#)):

Yeah. Um, I became a breast cancer Ireland ambassador very soon after my treatment ended. And it really gave me a sense that I was able to give back to other people, you know, um, after my experience and there's been so many highs, um, we had great fun with, um, events like battle of the stars where even though I can't dance, um, we managed to raise a lot of money and make like lots of friendships as well and raise awareness. Um, the great pink run is always a day that's, uh, Jo in my diary and, you know, I've roped family and friends into it as well. And it's, it's, there's something magical about that, that particular event and being an ambassador and being at the start line is always just a really, really special moment for me. And it's just to see the, see a pink behind you, and everybody's there for a reason and it's to help raise funds for a research, but it's also a lot of it can be remembering people and they're doing it for somebody mm-hmm <affirmative>.

Speaker 2 ([17:03](#)):

And when you get that many people in one place who are all there to do something for, for the same reason, it's really powerful. And then when you see the color pink, it just that sea of pink. See you think, yeah, it's just very special. Um, I've also done things I've gone down to the plowing championships. Um, I've done my Wellington boots and, um, you know, I, I done a talk down there and, um, that was, that was, that was really, really good, fun, um, and really interesting to, to see, you know, people who probably wouldn't normally attend the talk about breast cancer awareness, listening to what I had to say, you know, mm-hmm <affirmative> and, uh, meeting fellow, uh, breast cancer survivor on Yala as well.

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Mm-hmm <affirmative>, uh, which was really, really nice. Mm-hmm, <affirmative>, there's been so many things over the years that the, um, hundred K and 30 days has been brilliant. And it's a great thing to keep me doing my steps, you know, mm-hmm <affirmative> and, um, I guess the past two years it's been pretty challenging, you know, to try and keep people United together.

Speaker 1 ([18:09](#)):

Absolutely. And I suppose, you know, you talk about the a hundred K in 30 days, and I know they they're, they've just recently launched and we're really, really delighted to be the beneficiary of their fundraising once again, this year, the third year in a row, because those funds are making a massive difference. Um, in our research efforts, I mean, we have a new clinical trial that they're funding. So, you know, all of this is so, so important and you, and all the other ambassadors that support us, you know, you play a massive role in helping us to change this landscape. And I suppose as this is the last episode in our first season of more than a lump podcast, I have been probably asking all the questions all the way along. Have you any questions that you would like to ask?

Speaker 2 ([18:49](#)):

Yeah, it's great for me to be able to ask you a few questions, Ashley, and one question which I'm really interested, uh, in is, um, obviously breast cancer Ireland do a lot of research into new treatments. Um, so I'm interested in what is happening. What's the latest, um, treatment studies I've been.

Speaker 1 ([19:09](#)):

Yeah, that's very interesting. And it's something, you know, we try to, I suppose, through our, through our digital media and other resources, we try to explain to people, you know, the power of the investment in research and how important it is. Because I suppose over the years, we used to say, you know, we'll never make, we'll never get a final cure for all subtypes of breast cancer, but we'll certainly make that difference and try and transform the disease into a treatable long term illness. But what has been interesting is funds that we have raised in the last couple of years. And I suppose even during COVID times, which was really challenging because we couldn't have physical events, obviously because vulnerable populations, you know, restrictions were in place. But yet during that time, we shifted our business model to become much more of an online environment.

Speaker 1 ([19:52](#)):

We talked to our stakeholders, we asked them what they wanted to know more of. And yet they really wanted to know, like you say, about our research, about our education programs and how they could help in their own way, in their own local communities. So for the, I was just talking earlier about the hundred K and that initiative that was organized by Nile Carol and his wife, Kara, um, that they have raised over 3 million euros in the last two years. And the funding for them that they have, that they have raised has gone into creating a bespoke new clinical trial called the Shamrock trial. That's about to launch later on in June. And that is looking at a particular subtype of breast cancer. So these are her two positive breast cancer patients. And it's looking at sometimes there can be a recurrence, a very small percentage recurrence of patients after five years in this area.

Speaker 1 ([20:38](#)):

And what we're looking at is, uh, fourth generation drug and the power of that drug that will deescalate the need for chemotherapy as the next treatment plan. So in other words, a patient comes back with a

recurrence of her two positive breast cancer. We don't wanna give them chemotherapy anymore. We have this fourth generation drug. So what we're looking at is through the trial is we give the fourth generation drug. We give them a month of chemotherapy. We will deescalate chemotherapy completely and continue on the fourth generation drug. And what the scientists are saying and teams are saying is that we will get a 100% response rate in the next two to three years. That means we will have cured her two positive breast cancer, which is phenomenal. Wow. Another area that we're looking at, and it's an area that you, you know, as well through the ambassadors that have been on our program is triple negative breast cancer.

Speaker 1 ([21:28](#)):

That's a, a subtype breast cancer that tends to happen to younger women. It tends to be very aggressive. Um, and the, at the moment, the research hasn't been invested in to allow it get to a point where we can give new drug therapy to these patients at the moment they go through the age old of chemotherapy surgery, radiation therapy. So these are a young cohort of women whose fertility is massively affected because of chemotherapy. And therefore, what we're trying to say is they always have to go through fertility treatment and freezing eggs in advance of ever starting. Like you said, you were too late, you had to start straight away. What we're trying to say now is instead of putting the ravage of this on younger women, can we not come up with newer, more effective drug therapies that will avoid chemotherapy being the only point of call for, for a lot of these patients?

Speaker 1 ([22:14](#)):

So we're working with the team in Queens university in Belfast, um, and they are at the moment, their research has got them to a point where they feel they will about they're about to go on to clinical trial. They see promise in new drug therapies and how things are reconfigured. And I suppose one of the things we want to see is we wanna speed up our research discovery. And we've been doing that over the last 10 years. Each center in the last 10 years ago might have produced one peer review publication in say 24 months. We're now seeing each of the centers producing, you know, volumes of 18 and 20 papers that are peer reviewed in a 24 month period, which is fantastic.

Speaker 1 ([22:59](#)):

But it's now we wanna see is we wanna speed up those papers, getting to clinical trial because clinical trial is where we make a difference because we either repurpose drugs or we come up with new therapeutic drugs for patients, and that's where we're seeing the investment is needed. Um, and then we're also, as you know, working with our team based at the Royal college of surgeons into brain metastasis and brain metastasis is probably the most challenging. And it's one where we feel we need to invest quite a lot of money because when somebody has a metastasis, in other words, they've had an initial breast cancer treatment. There has been a recurrence, but at that point, the tumor has the cancer has EV evaded the initial treatment and has moved on into major organs and go into the, into the lungs, the liver, the bones, the spine, but it can go into the brain.

Speaker 1 ([23:44](#)):

And that's the one we really want to avoid. We can treat, we have new trial drugs that are there to treat the ma other major organs, but the brain is such an enormous organ in our body. And so sensitive that we're trying to do everything we can to prohibit the cells from traveling up into the brain. Um, and that's, that is we have done amazing work in it, but we still always have more to do, you know, it is not, we can't

just sit back and say, well, we're done. We have to keep pushing the boundaries. If we're gonna get to that point where we transform it into a long term treatable illness.

Speaker 2 ([24:16](#)):

And have you from when you, uh, took over as, um, CEO of breast cancer, and have you noticed, um, the time that people live with stage four cancer extend mm-hmm,

Speaker 1 ([24:32](#)):

<affirmative> definitely, I mean, we have seen people whose lives have, are people who are living with stage four cancer, and, and these are people where the cancer has. Yes, it has gone into their organs, other major organs, liver bones, et cetera, but they're on clinical trial drugs and they are living with cancer and maintaining their lifestyle, which is fantastic. We have unfortunately lost some people and we've lost our dear friend or burn, um, and Adele cannon and Fiona Lambert in the space of a year. But they were women who had been living for the previous four and five years with cancer, but it did UN unfortunately go to their brain. So more and more, the reason that I'm passionate about the continuous investment that's needed into metastatic brain disease.

Speaker 2 ([25:14](#)):

Yeah. It's, it's, it's it so hard, I think for breast cancer Ireland, when we do lose one of our ambassadors and unfortunately the reality of breast cancer is that people pass away with it and the research is amazing. Um, but it's not possible without fundraising. So, um, what plans do you have for the summer and beyond for fundraising and raising these vital funds for this very important research?

Speaker 1 ([25:48](#)):

Yeah. Um, I suppose now that we're coming out of that COVID blur and the pandemic blur, we're delighted that we're able to come back in a physical sense, um, with some of our physical events. And so this coming October, we will have our great pink run back in both the Phoenix park and in any castle park, which is great. And as you said earlier, you know, it's amazing to see that sea of pink. And it's a hugely emotive day. I often stand in the park on a Saturday morning early, and it can be lashing outta the heavens and I'm giving out because it's raining, but nobody else seems to have a grumble. Everybody has, you know, rain gear on they're smiling, they're happy and they're going past me in their thousands, um, supporting each other. And that's what I love. And that's what I missed during COVID is that physical sense of that physical camaraderie now, to be fair, though, people have rallied online in a virtual sense in their communities, which was phenomenal and really, really, um, delightful to see.

Speaker 1 ([26:42](#)):

Um, and we raised significant funding, um, throughout that period. And we will raise that money again with great pink run this year, because we'll also having done a, a research poll. We will have it in a virtual hybrid environment. So we'll put on our physical events for everybody who can come, but for those that it is doesn't suit them to come to those locations. They can do it in their localities, um, and be part of, and share the experience as well. And then we hope to have a lunch in June, uh, for our ambassadors and friends and supporters of breast cancer Ireland. Um, we also, as I said earlier, where the beneficiary of the a hundred K, which is happening in June, which is really, really fantastic, and it's, they are really focusing this year on that whole village atmosphere, communities getting together locally in their villages, in the country and extended beyond that to help raise funds for research. Um, so we've lots and



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lots planned because we have to, but what has been phenomenal has been the support that we've get from the public. We don't get government funding, um, but the public have been enormously generous. They, you know, they run their own events, whether they're doing marathons or cycle challenges, or, you know, fashion shows or coffee mornings or whatever, but they have been phenom, phenomenally, um, supportive of breast cancer Ireland. And that then ensures that we keep investing continuously into research.

Speaker 2 ([27:59](#)):

So I think you've answered all my questions actually. <laugh> so I'll hand it back over to you.

Speaker 1 ([28:04](#)):

<laugh> I keep the 1 0 1 on breast cancer Ireland. Uh, there, thank you so much for joining us today. It's been a pleasure. It's great to see you again. Um, thank you for all of your years of support and work as an ambassador for breast cancer Ireland, you are one of our beacons. Um, we really value your support and we look forward to working with you the future. Thanks Teresa. Thank you. Thank you so much for joining us for season. One of more than a lump podcast brought to you by breast cancer Ireland. Join us for season two later on this year. If you need any further information or would like to listen back to any of season, one more than alum podcast, please go to breast cancer. Ireland dot a more than a alum podcast is also available on all major podcast platforms. I'm Ashley Hurley. And thank you for joining us for season one of more than alum podcast.