A diagnosis of breast cancer can cause a lifechanging 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 Aisling 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 connections to breast cancer – be it through their career choice, their own first-hand experience of the disease, or through sharing the experience of close family members. My conversations will centre on how breast cancer has informed their perspective on life, love, family, health, their goals, and 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.

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Ann Eble was 48 years old when she was diagnosed with breast cancer for the first time in 2003. Anne joins me today along with Carol Mallon, who was diagnosed in 2004, and Maria Egan, who was living with a metastatic diagnosis. Each of my guests here in the studio with me today have dealt with their diagnosis differently. They have each had different side effects and challenges associated with their treatment, but importantly, they have found ways to live their best lives with their families and friends despite the trauma of what life has thrown at them. Welcome to More Than a Lump, Ladies. Thanks. I, Thanks Ashley Ann and Carol.

(<u>01:47</u>):

Uh, we've all become friends over the many years that you've been supporting and fundraising for breast cancer and you've attended loads of events and photo shoots together. Um, you've both danced your socks off at Battle of the Stars, helping to raise thousands of euros, but also it has to be said having great fun and some good laughs along the way.

Marion, I'm delighted to meet you again recently having originally met when Breast Cancer Ireland helped the Plurabelle Paddlers get their first Dragon boat back, uh oh many, many years ago. I'm very aware that all three of you have a very different story to share with our listeners, but I really wanted to devote an episode of More Than A Lump to some practical advice and some proactive and positive things and activities that can be considered to help women along their journey.

I also wanted to have an honest discussion on the side effects and the activities that can help. I'll kick off with you, Ann. You were diagnosed with stage three breast cancer in 2003. You had a mastectomy, six months of chemotherapy and 36 sessions of radiotherapy. For over 10 years, you were cancer free while taking a new drug. But three years after finishing the drug, you began to feel unwell and you were diagnosed with a different subtype of breast cancer in the other breast. Talk to me about when you received that second diagnosis and what practical things you'd been doing in those intervening years that may have actually helped you in the second time around.

Speaker 2 (03:03):

Well, I think the second time around was absolutely shocked. I thought I was thinking back of it now, I think I was more shocked the second time than I was the first time. Mm. And like the first time was like

19 years ago, so it's a long time ago. So the treatment we used to get then was dreadful. Like I know it wasn't, I shouldn't probably say dreadful, but it was a lot harder than Oh, and

Speaker 1 (<u>03:23</u>):

It just so

Speaker 2 (<u>03:24</u>):

Changed. Yeah. It's so changed now. It's, I mean, that's how I can see the difference in all the money going into research and how we have benefited over the last like mm-hmm. <affirmative> 19 years because 19 years ago, I know I put on six stone and weight. Now what? Because I wasn't, with all the, the treatment I was getting, I just literally, I mean, I was modelling around. I just couldn't believe it. So I couldn't really go for walks and um, I got every side effect going that you possibly get. Um, uh, and actually what I'd done then, even though everybody's doing, and now as I took up cease women in the 40 Foot Wow. So that's where I was found every day because I wouldn't have the, to go out walking or go after activity, I had to be very careful where I went because of the treatment. So I used to go down every day and I'd stay there for quite a lot of the day and I made loads of friends and we'd go for little walk and we'd catch up on the news and mm-hmm. <affirmative>, whatever it was happening in the world. Mm. That was all discussed then, and it was great.

Speaker 1 (<u>04:21</u>):

Yeah. And then 19 years later, a completely different type of breast cancer in the other breast

Speaker 2 (04:26):

Completely different. And because I had been on, um, a re a drug for 10 years from Beaumont Hospital under Professor Hill and my 10 years was up and I was over at the moment. Those 10 years were, because I thought, yes, because I suppose in a sense I probably had put on a little bit of, I mean, I blamed the tablets. I dunno whether tablets could have been me, but I blamed the tablets I'm putting on the weight. But I do know when I finished the tablets, I happened to lose weight, quite a lot of it. And I was pure delighted with life. And I thought, Well, this has cured me completely. I just feel on top of the world. And in that time you had taken up doing all this Battle of the Stars and you name it. And I was there.

(<u>05:08</u>):

And I have to say it was fantastic. I mean, that helped people so much. And I don't think people realize how much, uh, support it gives to people that are going through treatment or have been, or, or it's sort of bit of normality back in life again. Mm-hmm. <affirmative> and that you can take part in something that other people that has nothing wrong with them Sure. Doing. Sure. So I found that I just felt it was fantastic. Made loads of friends like Carol, I've only met Marion today, but, you know, um, I just felt it was fantastic amount of people, the fun that we had and all the people that we met. And of course my fine thing is, you know, , I still was going to him for my annual checkups, and it was coming around a time I think we had not long after a coffee day.

(<u>05:50</u>):

Cause I know we were coming around too. Um, and I was due a mammogram. And one of the girls, I also remember, she brought me a morg with, uh, you were born with theater and your bones or, or your veins or something. Yeah. And I was in washing it and it splashed on me Uhhuh. And I don't know what made me think Uhuh, that's something quite different. I haven't felt that in years. Right. And I knew I

was due my mammogram so I thought I'll wait. I had actually been in with Prof Hill, given a check in Uhhuh, and we were getting fo and I was going to say to him that day, and then I went, Oh, oh, I'm in two weeks not thinking, no, you know, it's nothing. It's just some, I'll wait for my two weeks. And I went in, It was lovely girl, I think I had for three years before that.

(<u>06:32</u>):

And she said to me, and How are you? And I went, Oh, I don't know. There's something. I said, It could be nothing. And I remember I was going off on my holidays and she said, Oh, I, you know, if you get a note now, don't panic your out just because you've told me something. You know you're going to be probably called in. I said, Grant, I went off from my holidays,

And I don't, I don't think he believed it. Yeah. So when you had to actually tell me, I think God helped. I felt more sorry for Prof Hill than I did myself. Yeah. Even though I was shocked, I think I was numb. Mm. Cause I thought, How could I have it? And there was no lump. Yeah. There was no uncomfortness. Like there was nothing absolute nothing. There was no tiredness. Like where before that I, I've always said this, Your body is trying to tell you there's something wrong. Mm-hmm. <affirmative>, but only for, I got a splash. Something so simple. There was no lump, there was no rash, there was nothing. Wow. So that's how, um,

Speaker 1 (07:43):

When and the treatment plan that you were on the second time around.

Speaker 2 (07:46):

Oh, so much. No, it's still not pleasant, but a hell of a lot shorter mm-hmm. <affirmative>. And it was, I was not, anyway, as sick as what I had been. So I could see the benefit of 19 years ago against in the last six years. Yeah. So six years ago when I got the second one, which was a completely different cancer mm-hmm. <affirmative> not, you know, but the first cancer was a tumor. This one was Lobber. Yeah. So there was no signs. And apparently I think that's the most dangerous of them because you don't get any lumps and you don't get any, you know, of the norm of what you're looking for. Absolutely. As I said, it was something as simple as hot water. Splashing.

Speaker 1 (08:20):

Yeah. Yeah. Unbelievable. And moving to you, Carol, you were 15, you were in your fifties when you were diagnosed. I remember you telling me that your enduring memory was being wheeled into an operating theater and worrying that you'd never wake up from the operation to see your husband and six children again. Can you share some of the practical advice you would give to someone in their midlife who's about to face into that kind of course of treatment?

Speaker 3 (08:42):

Yes. Yes. Well, I think at that stage, uh, I was full of fear. And, uh, the fear had overtaken my thoughts and everything really. And also a fear, really, not myself and my illness. It was fear of, uh, frightening everybody around me, especially our kids. And, uh, because at that stage, you know, so many years ago, there wasn't enough explanation of what is really cancers all about. It was the big sea. And everybody, you know, thought, Oh, it's a finale, But far from it, really. And I remember been so excited when I came out of a theater and just saw all my family around there again to greet me and say, Mom, it's so lovely that you're here with us. Mm-hmm. <a firmative>. And it was a lovely moment. I know it shouldn't be a

lovely moment, but, um, I think it that brought me joy that I got over that big Yeah. Big event. The terror. That was that the terror of it really.

Speaker 1 (09:46):

Yeah. And were you breast aware, like, were you going for regular mammograms? Were you, you know, I suppose conscious of how to self-check? Or was this just out of the

Speaker 3 (09:54):

Blue? Out of the blue? Not a thing. I hadn't a clue, really. I think I, I'm one of these people who don't go really looking for trouble. And in a way, it's a type. The avoidance ain't great either. But that's the way I followed it all the way through. Just wait until, and I know it's not fair to say wait until really the crucial moment, but I, I was not, uh, aware.

Speaker 1 (<u>10:20</u>):

And so you didn't check, you didn't find it yourself. It was probably through a mammogram.

Speaker 3 (<u>10:24</u>):

Mammogram. I always had, you know, slightly lumpy breasts. Really. And I had this lump on my breast for many, many years. Oh, good. Few years. And I went for a hysterectomy, and I was checked at that time, and there was nothing about the, the lump really. And then when I went, uh, for a mammogram, this lump became a bit, they were curious about it and sent me, then I went to, uh, surgeon and diagnosed it as malignant. Now after the needle biopsy? Yeah. Initially, but I had this lump for many years, but it was actually hidden. Okay. To a certain extent. Okay. And so probably with age, maybe it became more prominent, but I never thought that it was malignant, but it was

Speaker 1 (<u>11:10</u>):

Mm-hmm. <affirmative>. And what was your, your treatment was, uh, radiation therapy. Yes. Yeah. And obviously hormone, entire drug therapy for a couple of years after that.

Speaker 3 (<u>11:18</u>):

Yes, yes.

Speaker 1 (<u>11:19</u>):

Yeah. Mm-hmm. <affirmative>. And it's amazing, as you say, and as, as Anna has said, years, like years ago, back in the early two thousands, the treatment was very different to what the treatment is today. Yes. And we know that through research, we know the advances we're making with new clinical trial drugs and that, that life and everybody's treatment before you possibly all got the same type of treatment. Yeah. Mm-hmm. <affirmative>. Whereas nowadays, we know it's all personalized medicine. Yeah. It's personalized treatment plans for very specific genetic profiling, which is key. And I suppose to you, Marion, you were initially diagnosed nine years ago with early stage breast cancer. Can you

Speaker 4 (<u>11:52</u>):

Tell us us a little bit about your story? Yeah. So I was, to give my age away now, I was 41 when I was diagnosed. I had no family history. Um, I had a, a pain in my breast actually, which is usually we're told a good sign. And I thought, in all honesty, it was just where maybe an under wire bra was rubbing or something like that. And it was, I was just aware of it for a few days and I kind of had a little feel, but there was a distinct lump. Now, I did not check my breasts because in all honesty, I thought, and I think a lot of us think these things happen to other people. It's not, it's not gonna happen to me. This all happens to other people, and I'm in my little bubble and I'm gonna be grand. And maybe it happens to older women.

(<u>12:32</u>):

So, so yeah, I, I was kind of aware of the pain. I had a little feel of it, and it was a distinct lump. So I kind of put my head in the sand for about a week, but no longer. And I, I kind of knew, I kind of knew it wasn't right. So I went to my, my gp and she was very quick. She just said she had a very low threshold for referring. I went during my lunch break and work, and by the time I had got back to my desk in work, I had a call from the consultant's office to, to, for an appointment. And I knew at that stage she was concerned. And then I went in and the consultant did an exam, and he said he wasn't sure, but they'd send me for assessment. And I went then for an assessment, the couple of days later, I had a, a mammogram.

(<u>13:16</u>):

And they said if they saw anything, they might do an ultrasound and or biopsy. And I had all of it. And I, I knew, I knew immediately. And they said, Well, you know, will you, My husband was there. And I came out to him and I said, I think there's something. And I think they think there's something. So I think it was really clear to me early on. So long story short, I was diagnosed with stage two hormone positive breast cancer. So I had, I had to have a number of surgeries. They thought initially I'd get away with lumpectomy, but I didn't, uh, they thought it wasn't in my notes, but it was in my lymph node. So I had a full clearance as well. And, uh, then I had to have a mastectomy as well. So I had three surgeries at that stage after never having a surgery in my life.

(<u>14:00</u>):

My biggest fear actually when I was diagnosed was that I'd have to have surgery. Like our, that was what I was fearful of. It wasn't like cancer. It was, this was terrifying to me. Yeah, that sounds silly now with kind of all these years later. But it was a terrifying thing for me. And I had three kids and, and how to tell them, and they were, my eldest was a 15 year old boy. It was difficult for him with his mom having breast cancer. And then I'd, I'd, uh, 11 year old girl who, you know, had said to me, Well, her friend, her auntie had found a lump and it was cancer and she died. And was that gonna happen to me? And was it genetic? Even though she was only 11, she was concerned. And so all of those, and then my nine year old, and he was trying to mind his mommy and really difficult, my husband, trying to keep everything together.

(<u>14:50</u>):

But anyway, we went through it all, had the surgery, had chemotherapy, radiotherapy, and then I started on hormone therapy, had some issues around the hormone therapy, excuse me. Had some issues around the hormone therapy. And then I had to have a hysterectomy. Um, can I ask you why the hysterectomy? Just because they were concerned? No, they, no, I was having, um, really, really heavy bleeding. Okay. Um, on Tamoxifen. It was okay. It was a rare thing. I wouldn't want to anybody to be concerned. I was just a bit unlucky. So we had a bit of investigation and I needed a, a hysterectomy that was recommended, and that's what I had. And I went to my consult, my oncologist at that stage, uh, a couple of months after the hysterectomy. And I just said to her, You know, I'm just not feeling like I'm bouncing back like I thought I would.

(<u>15:40</u>):

I remember one of the nurses in the hospital saying to me, It's the best thing ever. You won't know yourself. You'll be flying. And I didn't, I wasn't flying. And I went to my oncologist and I said, You know, feel free to give me a kick up the backside here. I just don't feel, She said, I will not give you a kick up the backside. You know what? I was about four years out from the initial diagnosis, she said, You know what, we'll just do a CT scan. It's probably hormonal, but we'll just check. And then, um, so I had a CT scan, and that was in 2017. And they found what they thought hoped was a cyst on my liver. And it turned out not to be a cyst on my liver. It was a tumor and it was breast cancer that had spread.

(<u>16:19</u>):

So I was hugely unlucky, but I was also incredibly lucky because it was one spot and it was operable. So I had a liver section. Okay. And then I had to do it all again. So I had chemotherapy again. But I knew, you know, second time around, um, I think, you know, at least you know, the mountain is in front of you, but you'll know you'll get there. Um, I was able to cold cap that time. I didn't lose my hair. That was easier for the kids because for me, going to the school, it, it was hard for them. I was really conscious of how hard it was for them. The first time round. So did chemotherapy again. And then I started one of these targeted therapy treatments that you, um, mention Ashley and, and why I'm so grateful. And I love what breast cancer Ireland are about.

(<u>17:05</u>):

I started Pablo Cyc clip. Oh, yes. And I was on that for about three years, and I've been able to drop that now. And I'm just on, um, a hormonal treatment called anastrozole. Okay. Um, which is really hard on my joints, but it's a tablet I take every day and I'm keeping well, and I'm so, so thankful for the research that has me sitting here. You would never know, I think any of you would say, you would never know to look at me. Absolutely. And, and I attribute that to the treatments I've had. But also, you know, I remember my oncologist and my radiation oncologist saying to me, The best things you can do for yourself is keep active and try and keep a healthy weight. And I really believe in personal responsibility. Like I want to help myself. I'm not gonna be passive about this. So that's what I've done. And, and here I am today, thank God, five years later and doing so well and, and so thankful for it.

Speaker 1 (<u>17:58</u>):

Yeah, absolutely. And I, you know, I talked to so many different people throughout the course of the podcast and otherwise, and really clinical trials have come on hugely. Like there is a fantastic drugs now available for metastasis to the liver, to the bones, et cetera. I suppose the most challenging one is to the brain. And that's one that we are constantly investing in because it requires a significant amount of money. And we're doing a huge international collaboration with the likes of the Ludwig Center in Chicago. And we are making headway, which is great because I do want to get to a point sooner rather than later, that we transform this disease into a treatable long term illness that can be maintained. That's the ultimate end game. I mean, we got a vaccine for covid, for goodness sake, globally as we all came together. So why can we not, you know, really come together and do this for this particular cancer?

(<u>18:43</u>):

Um, tell me about the Loral paddlers, because I suppose way back in the early days of breast cancer, Ireland, I will remember Fiona Lord Mercy and are coming to me and saying, Oh, Ashley, we would just

love, we've no money, but could breast cancer Ireland support us with the purchase of one of the dragon boats, the hsc? I think we're gonna do the other one. I remember thinking to myself, What is this about? Yeah. And when she explained the benefit of the rowing action with women who have lymphedema post-surgery, you know, a stiffness, et cetera, or, you know, a swelling that to avoid it or to, or to alleviate it, um, it all became really, uh, under un relatable, I suppose. And I remember saying to the board, Look, we have to support these, these people. This is a great thing to do in the community. Tell us a little bit about your involvement with them. Yeah.

Speaker 4 (<u>19:28</u>):

We're so thankful to you for that actually. Um, Solu Paddlers were the first, um, Dragon Boat Club in Ireland. It's, it's a breast cancer club. It's, it's all breast cancer, um, survivors. Um, so it started in 2010 and thanks to to BCI in part, um, I learned about it in the hospital actually after having my, um, auxiliary clearance. And the physio came in and I was petrified of getting this thing called lymphedema. Oh my God. It sounded horrific. And you know, they ha they at the nurses as well. They, they, they were very well intentioned. They were trying to educate me. I was terrified in all honesty about lifting a shopping bag. Yeah. It was like, what is this thing going to happen to me? There's so much fear around the diagnosis. You're just, I think, paralyzed nearly. But anyway, one of the physios mentioned the plebe paddlers is cuz I was saying, What can I do?

(<u>20:19</u>):

What can I do to help myself? That was really what I wanted. And they mentioned the breath, the plebe paddlers. And I thought, that sounds terrific fun. So when I was through all my treatments and I'd had my reconstruction and everything, I joined the plural Belts in 2016. And in all honesty, I am not a very naturally outgoing person. So it's really out of my comfort zone to join this big gang of women with all these wonderful personalities. And they're loud and they're proud and they're brilliant. Um, and it was, it, it, but there was something there that really kept me coming back and they were so warm and welcoming. It was overwhelming for somebody like me. But I kept doing it because I knew in my heart of hearts it was really good for me to do it. And uh, so I joined in 2016 and I was really getting into the swing of it.

(<u>21:11</u>):

And then I had the recurrence in 2017. So I had to stop when I was going through chemotherapy again. And I have to credit them in all honesty, with saving me in 2017, because I was on, I was devastated. I was on my hands and knees, both physically, but mentally as well. You know, a, a metastatic diagnosis. I didn't know if I'd see that Christmas. Yeah. Or if I saw Christmas was not my last Christmas. Mm. And they just, you know, metaphorically, I suppose embraced me. They supported me not in a, a real, in your face kind of way. They check in any time. Um, I'd go down, you'd be welcome for a cup of tea when I wasn't paddling. And then as soon as I'd finish chemotherapy again, um, you ate three months and then you can go back paddling. I didn't know what I'd be able to do when I got into that boat that day and I was able to rebuild myself in all honesty.

(22:04):

And you know, they take you as they find you, um, everybody all ages, all ages from, we have members, uh, in their thirties right up into their seventies. There is a place for everyone in that boat. Um, there is some women that are really competitive. I'd be fairly competitive now and never thought I was <laugh>. Um, and then there's some that are, they just wanna go and paddle around and have a bit of a laugh.

That's okay too. It's whatever, There's something for everyone and it's just, I have to say they have taught me how to live again. They are the most wonderful bunch of ladies. I'm so, so grateful to them.

Speaker 1 (22:40):

And Carol, you, in your, you know, a couple years ago, I know ge definitely before Covid, probably maybe five or six years ago, you were very involved with L be too. Yes. And you loved that whole camaraderie and support of all of these women.

Speaker 3 (22:52):

Yes, absolutely. Amazing. And even the workup before starting, you do the exercise together, there's a togetherness in it. Yeah. And then there's always somebody if you're new to help you into it. And imagine, I would often say it to people, Well I'm going to row a boat now and let's say you are going to row a boat. How can you do that? Well just with the help you just got into it and these big heavy oars. Mm-hmm. And you are pulling back there. You're in the middle of water. There's no, there's no, uh, danger of anything and no talk of any sadness. It's all go. And also, and it helps the bingo wings as well. You probably don't know what that is. You're all too young. Caroline don't have

Speaker 4 (<u>23:35</u>): Any bingo wings. Now will you stop?

Speaker 3 (23:37):

So it was lovely and the support was, was fantastic. And the water, the whole exercise game

Speaker 1 (23:45): Was, there's something very calming about Waterworth.

Speaker 4 (<u>23:48</u>):

Sure. I I find it. He, I I would say it's healing. Yeah. I, I think for me it's healing and we're so lucky we're in the Grand Canal dock and it's just, there's a bit of life around it. It's lovely. But Saturday morning in particular and say last Saturday morning, the weather was beautiful and the sun sparkling along the water. It's just so peaceful. Calming, I think healing. Yeah.

Speaker 1 (<u>24:10</u>): It's those ions.

Speaker 4 (<u>24:11</u>): Heavenly,

Speaker 1 (<u>24:12</u>):

It's the ions that kind of combat the whole mm-hmm. You know, the city and the smog and the stress and all of that. And then you get the water and it's like, cams it all down. Totally.

Speaker 2 (24:21):

That's not why everybody took to the water and jump before Calver. I think so. Yeah. Like, you know, you, you've been there for a long time before, but it's like everybody, it's like Sandy Co the 44. Yeah. Couldn't get near the place. I know. I mean, for years we were going having a great time and then you can't get, when everybody should have been separated. We were all like, well,

Speaker 1 (24:38):

You ahead. You were headier again 20 years ago. Are you swimming? But listen, all the dry ropes around at the moment and I, I didn't know what I have one too.

Speaker 2 (24:46):

I remember actually funny enough when I went down cuz the women were saying them and the men actually, cause we used to have great sing songs. It was somebody's birthday, they, the cake be brought down and everybody was saying, and in the wintertime they used to have brandy and the butter in their tea and the coffee, I can tell you wore you up really party time. I was part of the 11 o'clock. They were fantastic people and raised a lot of money for cancer. They did as well. And, but like, it was such to be get up as you're saying, going down there to get up and know you're going down to see. It was like as if somebody just, it was like being baptized again. Getting in and getting out. You were two different people going down and getting out. You know, it's, it's just, I think it's healing to me. Whether it's in early in the morning or late at night, if you are on the sea down near to say it's just like you're breed in it's heaven. It's like somebody's sending you some and I'm sure car you were the same when you joined us. I did try to join. I don't know what happened. Maybe somebody, somebody didn't answer. Are we get

Speaker 1 (25:39):

You in a boat yet? We will on cruises. No, no. We'll get you in one of those dragon boats. Love to cruises.

Speaker 2 (<u>25:46</u>): <laugh> Mar. But actually Mary and I have, we're like, aren't we like twins in our treatment? Yeah.

Speaker 4 (<u>25:50</u>): A lot of similar treatments. Very,

Speaker 2 (<u>25:52</u>): Aren't

Speaker 4 (<u>25:52</u>): We? Yeah. One

Speaker 2 (<u>25:53</u>): Of the things I was diagnosed,

Speaker 4 (<u>25:54</u>):

One of the things I have found actually, um, when I was going through the, the, this heavier treatment, the second time round, fatigue was a huge issue for me. And actually, and there was days where I really

just wanted to go back to bed. And when you, we, we have a, a little app and you sign up and you're committing to go to training and the boat and everything. I say, Oh God, I just wanna go back to bed. But I'll go because I've said I'll go and we need to balance boats and stuff. And you, you just go. And then there's a thing with exercise, uh, it seems counterintuitive when you're tired and you're fatigued. But actually if you can move your body, it really just energizes you and then you sleep so well the next, you know, that night mm-hmm. <affirmative>. So that was a huge thing for me. I noticed when I was going through treatment the second time around or you know, all that, that heavier treatment, um, when I went, there was days I thought, oh God, I'd just love to be in bed now. But I'd get into the boat and then when I was coming back in, when we were coming back into dark, it's like, Oh, I, I I'm still tired. But it's a different kind of tired. Yeah.

Speaker 1 (26:55):

The sea, the sea makes sea breeze or whatever it is about the sea makes everybody have a good night's sleep. I think the breeze, it's there. And what, what were your side effects like Carol, when you had your initial treatment, had you any kind of side effects that were

Speaker 3 (27:09):

Tough? Really, I, I couldn't say had any, probably a bit leaking, you know, around my breast type of thing. Which would, it was a little bit startling really. But I, I actually can't say anything because I, I've sort of, I think I was in another world actually and didn't think of really or didn't realize what was happening. Me as you were saying maram, the fear takes over and I just didn't realize. And also too, maybe I did feel a sense of now side effects, not the treatment but a little bit of loneliness in my head. I went on the journey on my own rather than a make other people fearful or kids, family and everything. And that was a little bit, it was a little bit isolating going for my treat treatment because I chose to do it alone but I wouldn't do it again because then I didn't, the kids didn't know what was happening. Was I going to survive? Was it very severe? Was I suffering because I didn't want to upset? Didn't want upset them, I didn't upset them. Yeah. And as you'd say, they heard stories and now they were quite adults, but they'd hear of somebody else and they hear something in television and to be reading the papers, Gosh, that's my mother has my God that we were going to be in the situation.

Speaker 1 (28:28):

Yeah. You put on the brave face like most mommy do. Which

Speaker 3 (28:31):

In a way wasn't really the proper thing to do for them either. Cuz I kept them in the dark and I was very much in the dark myself. But the way I looked at at it, there was light at the end of the tunnel. I didn't realize that. I kept saying there is light at the end of the tunnel. You're,

Speaker 1 (28:48):

It's amazing. I often speak to people and they would talk about, you know, the fear never really goes away. You know, no matter if you have it once, twice,

Speaker 2 (28:56):

It doesn't, don't know. I have to say I, and I know it sounds, I don't fear about getting anything out. Well after getting that the first time and then the second time. Mm-hmm. <affirmative>, I just don't think anymore. I think. And I think after being through what we've been through, I think it made us all stronger. Would you agree? In the sense I feel I could deal with awful lot of things more than I would've, I think I would've sailed. I think it was a person that used to sail through life. Life is for living and enjoying yourself and all that. And I think that it just made me stronger. There's lots of other things that has happened and when you have to do things and really it can be, even though with all your family and friends around, it can be a very lonely place. Because as I say to people, it's like anything be your faith or anything when you are are in the hospital at two o'clock in the morning, there's nobody else there. Only you, you have to have that conversation with yourself. So I think I just sort of, the way I got through both of us when I got a start date off, be it drop their cars off to find whoever it was, I start on that date and I knew I was going to finish. I'll

Speaker 1 (29:58):

Just interrupt you one moment because our listeners won't know who dropped dead gorgeous is and the fine thing. And while I really don't want to have this aired You do, I don't really <laugh> explain to them who dropped deaded. Gorgeous. And your fine thing

Speaker 2 (<u>30:10</u>):

Are okay, Drop dead gorgeous is David Femme. He is an ecologist in hospital and he has dropped dead gorgeous. But they were shut without 19 years ago and he still dropped that gorgeous. And my fine thing is Professor Ernie Hill, which you know very well and he is definitely improve with life. He's younger looking, he's getting

Speaker 1 (<u>30:30</u>): Now. I hope he's not listening. He's

Speaker 2 (<u>30:32</u>):

Fantastic. And you know something, those two men and and and other people have got me through, got me to where I am today because I put my trust in them. And like it's probably our friend and Carl knows Eve, she always says they sort of guard me in the sense. Absolutely. I'm not a person that wants to go in and say what's happening to you and what are you getting? Are you getting this and what's that tablet for? I don't care if you tell me to take, I'll swallow it. Mm-hmm. And that's it. I don't care whether it's what it does it

Speaker 1 (<u>30:59</u>):

Yeah, it's true. They're like the army on your working on your behalf.

Speaker 2 (<u>31:01</u>):

They do. And they, you know, it's like I, when I went back to, and like Mary was saying, I got canceled a third time when they, when I went for a checkup, I remember the consultant the professor had done where I got her on the lung. He said to me, you know, it could come back. And, and I'm like looking, thinking I'm really on the floor here. What he, you really tell me he's going to come back for it. And I ended up going back to drop that guard just for another check for, for I said it to him and he goes, You

were kidding me. He didn't say that to you, said don't mind him. I wouldn't have sent you for an operation if I thought that. And I go, you see, that's how I'm guarded. And yeah, everybody's, there's no need. I don't think. Yeah. I I'm just one of those people. I don't need to know everything. I just a need to know basis. Yeah. So it's, you tell me something and if I trust you and I think that's where the most importantly, would you agree that you put your trust in your consultants or your, um,

Speaker 1 (<u>31:52</u>):

What do you think Marian?

Speaker 4 (<u>31:54</u>):

I I absolutely, I I only see my oncologist now and I absolutely trust her at, at Janice Walsh. However I do, and I'm not questioning her judgment or, but I do like to understand why am I on this and not on that? What's this, what's the paal cy, what's that going to? Why am I having chemotherapy? And first before just for me, for my head. It's just I need to understand. Yeah. And once I, once I understand it, then we go and I'm not questioning her judgment at all, but I do need to know, and I am awful for Googling anybody who says to me, Don't Google, I just go on Google. That's exactly the wrong thing to do. Um, and I think that's just my way. And I, I always ha it's not really great for my anxiety to be honest, but that's what I do.

(<u>32:42</u>):

And um, and I know, you know, there's so many trials and there's so many things and that reassures me actually to know that I'm doing really, really well. God forbid. And we're not even going to go there in case it ever happened again. It won't please God. But I know that there's so much stuff in development and that's, so that's how I handle it. And that's absolutely, and I, what I would say is everybody has to find their own way of doing it. It's, you know, you do your way, I do mine. They're both right for us. It's whatever is right for you. And I would never advise somebody what they should and shouldn't do because unfortunately you have to find your own way. Yeah,

Speaker 1 (<u>33:21</u>):

I think, I think so.

Speaker 2 (<u>33:22</u>):

But that's why I'm saying they sort of guard me and I'm happy to let them do it because I think you enough to worry about in the day. So there is, and that's just a personal thing to me. Yeah. But I think like looking back, as I say 19 years ago and I am that child work for 10 years. Yeah. Like that kept that cancer away for 10 years. And to me now looking at younger people being diagnosed, it's not a death sentence anymore. Like I remember like 19 years ago, like it was the big scene. Nobody said breast cancer and nobody said it was always the big scene. You going, What do you mean? It was like, wait, can I tell you somebody the big scene?

Speaker 1 (<u>33:55</u>):

Yeah. What Big C No whispering about it. You know,

Speaker 2 (<u>33:57</u>):

It's, it's awful. Where I think now that people, you know, it's, to me, if if you hear I, it's not a death sentence anymore because it has really involved so much over the, the oh it has 19 years. Oh. With all the research now. And I, and I think, and I've said this before, they will eventually get that will be like, um, a diabetic getting treatment and wouldn't that be wonderful? And you can live to see your children growing up, not being taken away from you.

Speaker 1 (<u>34:23</u>):

It's, even if we look at this new, new clinical trial drug that's uh, that's where a new clinical trial that we've just started and we are breast cancer and just funding it. Um, it's called the Shamrock trial in the new Beaumont Breast Center. And it's looking at her two positive subtype breast cancer. And it's looking at recurrence that can happen and it can happen about 30% of to people who have had, uh, heart two diagnosis. But we're looking now at giving these people a fourth generation drug, got a big long name, I'm not gonna go there. And an initial chemotherapy for maybe a month, then deescalating the need for that chemotherapy and they continue on this drug. And we're, we're, we're predicting that in two to three years we will have a 100% response rate. So that's like tick box cure for that particular subtype of breast cancer.

(<u>35:04</u>):

And I mean never did, I think I'd get to that point over the last, you know, 10, 15 years in this space of that we will actually have a cure. Now unfortunately there are lots of permutations and lots of subtype, breast cancers. But at least if we do one and we get a positive response rate from that particular one, we're moving on. We're also supporting triple negative breast cancer. Uh, which again is um, a challenging one because it tends to happen to lots of younger women and they tend to, at the moment the research is poor. So we're trying to put a lot of funding into this research because they go through the age old treatment of, of chemo surgery and radiation therapy. These are younger women who are of childbearing age fertility is affected, they're plunged into early menopause. So we're trying to look at a way and say, can we not come up with a drug that is better where they don't need chemotherapy to damage the organs, but where, and to kill the, the tumor.

(<u>35:53</u>):

But we can give them something that's targeted specifically for the tumor and protects everything else. So we're doing that with Queens University in Belfast. And as I said, the other we're doing is in the whole area of metastatic disease because it's an area that there's lots done in relation to a lot of the major organs, but the brain is the one that we find most challenging. Yeah. So that's the one that we really want to, I think if we do that, then we have all remits covered, you know, and we, we get to that point where please God, you know, we, we are, we are not seeing any more fatalities. So Carol, I know that there was one particular, um, exercise that you, uh, took on, took on board as part of your, I suppose recovery and coming through the other side. Do you wanna talk to us a little bit about that?

Speaker 3 (<u>36:35</u>):

Yes. Uh, that was a wonderful experience. The dancing, it was amazing. How are the stars strictly, strictly dancing And with the help of Ash and the girls and Kira and Sam and everybody, it was like a, another big adventure in my life that I enjoyed so much. And it was part of the embracing recovery really. And also, uh, when getting quickly to the performance in all the wonderful places that you took us to dance and the rehearsal, the excitement regarding that was amazing. And I remember one in particular, uh, all of them were fantastic but especially in the convention center. And I was dancing to a candle, the walls

candle on the wind. Yeah. With Charlie by, which was a very memorable event really. And uh, Charlie came up to me and he said, You know, I can't put one foot pass another. And I said, Well here's your friend.

(<u>37:36</u>):

And I can't either. And we danced. We were like I said, a Ginger Rogers and Fred a stair dancing in the convention center like movie stars in front of a thousand people. And to me that was a most enjoyable and encouraging event because there were so many people out there who supported us, uh, came there because they were ill. The family was ill. Most of them would've been have experience of cancer. And there and Anne was involved in that too. And there we were like movie stars up on the stage. No fear. No fear, that's right. Of anything. And it was just fantastic. I'll never forget it on Candle in the Wind. That's right. And uh, what Elton John, uh, playing

Speaker 1 (<u>38:24</u>):

At

Speaker 3 (<u>38:24</u>):

For Diana. Yeah, that's right. And Princess Diana. Yeah. The whole memory of that. And as a result I did appreciate, um, Charlie even dancing with me even though his toes could have been a little bit damage <laugh>. So much so that I climbed Kirkpatrick for him this year. Come climb with Charlie and I was right there at the top with him supporting him cause it was payback time. He supported me and I supported him at 76 years of age. Oh my god. I know I shouldn't tell it. But it was published in the Sunday Times this day thought and this reporter came behind me and I think he said, Who is this old one? You know, how's she doing here? Yeah. So I just, in walking with him That's right. Sliding and him lifting me. I didn't know who he was. I told him my story. I came to support Charlie. Yeah,

Speaker 1 (<u>39:15</u>):

Yeah. Um, I can remember all those years ago when Charlie, I had approached him to do the dance with us. Um, and I said, you know, I'm gonna partner you with this lovely lady. And he initially, Yes, I'll come. I'll do whatever you want me to do. I'd love to help out. And then he went to the rehearsals and it was like, Ashing, I can't dance. This is really not for me. I really feel as if I, I've two left feet, I'm banging off Carol, I'm banging into the wall. I'm so useless. And I was saying, No you're not. You're fabulous. And to be fair, he stuck it out. And actually Claire, his wife, that's, she really was the backbone, you know, encouraging him to stick with it and that it would be right on the night. And it was fantastic.

Speaker 3 (<u>39:50</u>):

Oh, it was amazing. I will never forget it. Most memorable event. And thanks to all of you and Laura, Cs I and bci, you were amazing to you helped us

Speaker 1 (<u>40:02</u>):

Uhhuh and Anna, you took part in many a Battle of the Stars.

Speaker 2 (<u>40:06</u>):

<laugh>, I had such a great, um, I really did. I just think as Carl saying, because I think that was the first convention center was twice. And I remember that was Film Star. Like, I mean do you remember we

MoreThanALumpS2Ep8Audio_mixdown (Completed 10/20/22) Transcript by <u>Rev.com</u> went down with, I was with um, Eric Law. Eric Law and he was something else. I mean Eric Lawler was like, I was Tina Turner, wasn't I? That's right.

Speaker 1 (<u>40:27</u>): Big wheels keep on turning.

Speaker 2 (<u>40:28</u>): Who was Tina Turner's partner off? What did the awesome Par? So he dresses like

Speaker 1 (<u>40:33</u>): Was Austin

Speaker 2 (<u>40:34</u>):

And he had this purple suit on and I remember him said, Now Anne, we were at the door, you know when the doors are all That's right. We're waiting to open. And he goes, Just go in, do whatever you want. I'm telling you now. And I was looking, I thought we were to be, you know, walk up nice and all this. He literally worked that room with the window bed

Speaker 1 (<u>40:49</u>):

In. Nobody was fantastic.

Speaker 2 (<u>40:50</u>):

And he just said he pulled off his jacket and there was like with a babe and the, I couldn't stop laughing on stage cuz I hadn't seen this. Like I'd seen this proper suit, but this big thing. And I thought, oh my God. And we went down these like lim scenes down onto the where it was. And that was part of my, my recovery as well. Mm-hmm. <affirmative>. And like when Sam rang me that day and said, Anne, you're going down to me. And it was what me that's, I couldn't, but I'll tell you it was absolutely to make And we Macky and we met Ev everybody

Speaker 1 (<u>41:19</u>):

There's been so many people that have come together as a result of those, this types of events. There

Speaker 2 (<u>41:24</u>): Was that one with,

Speaker 1 (<u>41:25</u>): Uh, the one that Emma Henigan dance at. Oh yes.

Speaker 3 (<u>41:29</u>):

I,

Speaker 2 (<u>41:30</u>):

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Tina Jordan was brilliant. My gold Jimmy Dress and Boots still love them.

Speaker 1 (<u>41:34</u>): Yeah,

Speaker 2 (<u>41:34</u>):

Yeah. That was fantastic. Like we, we won actually, didn't we? The second we, we got the most entertainment. That's right. He was, No, I have to tell you, I was on the stage like in Stitch, I was like this in shock when I saw him with this big fancy Bri He was brilliant. And then, then Year Carol start met was with Adrian Kennedy. And like Adrian at that time they were sort of saying he was the mo of the south or the east or something. Yes. And he was this quiet senti. He was so, Yeah, that's right. He was absolutely petrified. Yeah. He, and I'm thinking, how could you be petrified you

Speaker 1 (42:04):

All the time? But you know, I suppose it's, it's events like that that people, you know, it's coming outside your comfort zone and it's doing things like you Maryanne and Plu Bells. You know, its something that you would never have thought you'd have got involved in. It's coming outside your comfort zone and knowing that there are people there who will support you all the way through. Well Anne and Maryanne and Carol, thank you so much for joining me today on our podcast, More Than a Lump.

Speaker 2 (<u>42:27</u>): Thank you. Thank you.

Speaker 1 (<u>42:29</u>):

The information in this podcast is based on the personal stories of those we have chatted to. If you are concerned in any way, please contact your GP immediately or you can contact us@breastcancerireland.com.