Bowel and vaginal cancer, and acoustic neuroma with Karen Bucknall

Speaker Key:

VO **Voiceover**

CB **Chantal Boyle**

KB **Karen Bucknall**

00:00:00

VO

Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB

I'm Chantal, and I have the pleasure today of being joined by Karen Bucknall. She is a pageant queen and model who uses her platform to celebrate her body and raise awareness of cancer for Macmillan. Karen has stage 3 bowel cancer which has spread to her lymph nodes, rectum and vagina.

Karen also has a stoma, wears a colostomy bag, and has a benign brain tumour called acoustic neuroma. It affects her mobility, balance and hearing, and creates pressure in her brain and ears. She also lives with hypertension, which is very high blood pressure. So, welcome to Karen.

KB

Oh, thank you for having me.

CB

Can you tell us a bit more about the beauty pageants and the modelling, and when did it begin?

00:01:25

KB

Gosh, it's only been ten months, so really, less than a year. And I entered an online Facebook competition, and they were looking for finalists to sponsor for a Miss Voluptuous pageant last July. And I applied, it was June 2022, it was my birthday month. I applied, and I got accepted to be a Miss finalist. Did the pageant, I didn't get any titles or any crowns, but then I went on to do future pageants like Warrior, the Kerri Parker Academy, Miss Sparkle, Miss Magical Smile, and Princess of Hearts.

And it's only been in the last, what, two months that I've actually been crowned a pageant queen, not once but three times, and it's still really amazing. I'm still getting my head round it.

CB

Well, that's a wonderful achievement. So, why did you decide to enter?

KB

I think, if I'm being honest, Chantal, it was because I was feeling so low after having had bowel cancer, wearing a colostomy bag, and lots of, I don't know if I can say the word, poo disasters. I felt really low, and I felt ugly. And I'm 52, I felt really old and fat and useless. And I wanted it to help me with my self-esteem, self-confidence, and a more positive body image.

00:03:02

I don't know any girl that hasn't dreamed of being Miss World when they were little and having watched it on the telly. That's why I did it, just to feel good about myself, and also to meet other girls that maybe were going through their own health stories, whether it was the menopause, brain tumours, cancer, mental health challenges. But yes, that's why I did it.

CB

I think that that is such a great thing to do, because as we'll get on to during our conversation, your body has been through a lot. So, to actually make that a priority, and put that up front and centre, and celebrate your body is just marvellous. I think it's really marvellous.

KB

Thank you so much. I've gone from hating my post-cancer, post-surgery body to accepting it is what it is. My scars, they tell my story. And my colostomy bag, which is for life, it will never be reversed, actually saved my life. I think, really, when you look at other girls, even the most beautiful, perfect, slim girls hate their body. There's something about their body they don't like.

So, I've learned to accept, embrace, value my body, and I'm now not afraid to share my colostomy bag on stage or in a Warrior charity pageant calendar, which is celebrating invisible illnesses and hidden disabilities.

00:04:42

CB

Good for you. So, when I introduced you, I listed quite a few things that you are having to live with. Can we go over them, please.

KB

Yes, absolutely. It's just one thing after another. They always give me these invisible illnesses that I can't pronounce, like acoustic neuroma, which is a benign brain tumour. It took me at least a week to say it properly, and probably at least a month to spell it correctly.

CB

I have to be honest, when I said it, I was like, I hope I've got it right, because I do struggle.

KB

I'm like that all the time. They always give me things that I can't pronounce, and I'm terrible for being Dr Google and going online. I don't know whether I should go back to university, go to medical school, and train to be doctor.

CB

Probably, the amount of research you've had to do.

KB

I'm not alone. I know a lot of bowel cancer survivors who have one thing after another. So, there was me thinking I must be a medical freak of history. It's quite common. High blood pressure, which is controlled by medication and diet and exercise. My colostomy bag, obviously I'm well looked after by my stoma care team.

The benign brain tumour, that got picked up a few months after I finished chemotherapy, when they released that the headaches I was having weren't caused by the chemotherapy drugs. It was actually something else going on. So, yes, it does seem sometimes like it's one thing after another, but like I've said, when I talked to other cancer survivors, whether they've had breast cancer, bowel cancer, they have similar things, there's always something going on. I have no… I can never say it, immune system.

00:06:52

CB

Right, your immune system's gone through your treatment.

KB

I can't fight off infection. I will always pick up a cold. If I'm near someone that's got a dodgy tummy, you can guarantee it will come through the stoma hole, I will get a dodgy tummy. I pick up all kinds of viruses. I have to be really careful with cleanliness, hygiene, which I am very particular about. And I have to avoid big crowds.

And when it was COVID, I had to always be isolated which, as most people that have had cancer would say, during the lockdown when we were shielding, we had to be hidden away, my life was home, back garden, hospital, and the little ambulance, the patient transport ambulance that takes you there and back. And because I couldn't get too near people, just in case they had COVID, but then in 2020 when I was having chemotherapy for my cancer, if I had got COVID, I would've been a really, really poorly girl.

So, those times were the most isolating, loneliest times of my life. I was cut off from family and friends. It was just Mum and Dad and me in the house, and then going to hospital was like a big social occasion. Oh, people, a little ride in the ambulance. Whoa, I'm so happy.

00:08:32

But on a sadder note, I was so isolated and lonely, and because I was backwards and forwards to hospital, I was beginning to feel very institutionalised. It's not a place you want to go down that avenue, where you see hospital as your safety place, your saviour, and you could quite easily have gone into that world. And that's why I love pageants so much, because I'm not lonely anymore, I'm not isolated, I'm not cut off. I'm with girls and women that have become really good friends.

CB

Good. That's very interesting that you say that the hospital was became your safe space and it became your sanctuary, and it's there to help you, but it shouldn't be the…

KB

In all fairness, Chantal, you shouldn't be looking forward to going to chemotherapy, because you're going to see the nurses and the doctors and other cancer patients. And when I was really poorly with sepsis, because I had a sepsis rash and I was really ill with all kinds of things that the chemotherapy was causing me to be sick, and all kinds of problems, you shouldn't be looking forward to actually spending three nights in hospital in a private room.

That's how bad it got. Ooh, respite from Mum and Dad, ooh, I'm on a little holiday. And that's why I said it was so easy to become institutionalised.

CB

Yes. And your acoustic neuroma, your benign brain tumour, do we think that that is a result of having bowel cancer and treatment, or do they not know if there's a link?

KB

Oh, it's a great debate, this one. There is research out there that suggests that bowel cancer and benign brain tumours are linked. But who knows? All I know is, my body keeps producing tumours, whether benign or cancerous. It started eight years ago with fibroids and cysts, and a benign tumour on my uterus, which led to a hysterectomy.

00:11:05

My oncologist said, your body keeps producing tumours, and there's nothing we can do about it, other than monitor you, and as soon as you produce another tumour, nip it in the bud, or put you on medication or in treatments. It's just one of those things. I said to you earlier, I feel like a freak of nature sometimes. It will continue. They've said, you'll never technically be cured. We can control it, we can contain it, but we can't give you that miracle cure.

CB

How does that make you feel?

KB

It makes me feel quite sad, quite angry. Why me? What have I done to deserve this? Eight years ago, when I had my hysterectomy, you said it would all be okay. And then, what, four years after my hysterectomy, I got a benign brain tumour, my first one, which is the nape of my neck, which does absolutely nothing. And then a year later, I got cancer. I was like, yes, great, thank you very much.

And after chemotherapy, I got my second benign brain tumour, which is across the acoustic neuroma line, and that is the one that gives me the most grief. So, it seems over a few years, and we're coming up now to the four years since being diagnosed with bowel cancer. My benign brain tumour has grown.

00:12:50

And because I'm having lots of problems with my bowels again, and lots of pain, they think, let's see if the bowel cancer is okay, or the cancer that's still in her rectum, if that's grown as well, like the benign brain tumour has grown. It's worrying, but it makes you live your best life ever.

CB

You have a very good spirit about you, and approach to life. You really do.

KB

Yes, I think you have two options. You can either lie in bed all day, wait to die, wait for the next tumour, wait for the latest bad news. Or you can go out there like Barbie, because when you have my bowel cancer, which is up the rectum, you have what they call the Barbie butt, which is the sewn-up bottom.

And Barbie movie comes out in July, I love Barbie. You can be like Barbie, and you can live your best life ever, and my life is like a Barbie doll's life. I'm not going to lie. I'm like Barbie, I’ve got the butt, I’m living my best life ever. And like Barbie, I like wearing pink. I’ve got a bit of pink on today.

So, you have two options, give up, or you carry on. I do a lot of work with cancer charities and brain tumour charities, as well as my pageants and size-plus modelling, which happened because of the pageants. You carry on, and you leave a legacy, and you encourage other women and girls that are going through it, that life doesn’t stop, that you can do pageants, you can do modelling. You can basically, like Barbie says, you can do anything you want to do.

CB

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00:15:06

The statistic that we hear now is that one in two people have cancer, which is shocking, and that there are different stages, isn’t there? So, you’re stage 3. What does that mean for you?

KB

What it means to me is, I was diagnosed as a stage 3. When it went into my lymph nodes and it went into my vagina, I then went into a stage 4. But I don’t like saying stage 4, because it freaks people out. I just say advanced, and I think that’s the softer approach.

Yes, I think the grading can put the fear of God into people, and then you start comparing. Well, she’s got a stage 2. Well, he’s got a stage 3. Oh, she’s only got a stage 1, isn’t she lucky? That’s how you do it. It’s like your degree. I left Coventry University, BA Honours in Sociology at 2:1, just scraped into a 2:1, bearing in mind I was very poorly with cancer.

But actually, you compare it and you think, well, you’ve got stage 4, oh my god, that is the end. A stage 3 is pretty bad, whereas a stage 2 is okay. Stage 1, it’s like, aren’t you lucky? Wow. But it’s not, because it’s been caught very early. But it’s a number game, isn’t it? And I think in this society, we do love our numbers, and we do like to have a high and low, don’t we?

00:16:48

CB

We do. We like to rank people, rate them.

KB

We do. We like to compare and contrast. Oh, you’ve got a stage 3, and then stage 4 just puts the fear of God into people. So, I technically, once on the operating theatre, they realised it had spread. I went into the 4, but I like to say advanced. You’ve got to be so sensitive with cancer, and colostomy bags, and brain tumours. You've got to word it in a way that people get it, but don't put the fear of God into them.

CB

That is such a giving way to approach it, that you are really concerned about how your health and how you describe it will impact others, as opposed to people reacting to you, and how they make you feel. The fact that you are worried and concerned, and you put that thought into how you are sharing your health with people that you know or don't know.

KB

Yes, that's a good point. I've never really thought about it. I think also because I trained as a journalist after college, and so we are taught how to say things. And I think that was always drummed into me. But a lot of my friends, I'm very honest about my cancer. Certain things I won't go into great detail, and that usually involves poo, blood and wee.

Because I've got a lot of friends that are going through the menopause, and a few of them are having hysterectomies. I could tell you horror stories about my early menopause, and my hysterectomy, and the bleeding. But again, I think it's just being sensitive and using the right words, and just saying it's quite common for these things to happen, without going into a great detail.

00:19:01

I think a lot of it is about reducing the shame and stigma linked to anything that's linked with women's bits, blood, poo, wee, cancer, brain tumours, because there's still a lot of stigma in this country.

CB

Yes, I know, but we all poo, we all wee. Women have periods, and men have other things that they experience. And we do need to reduce the stigma. So, thank you for taking part in this and sharing your story. It probably brings me on to the vaginal and rectum cancer. Looking back, were there any telltale signs?

KB

Yes. I think my most important thing is to say, before we go into the signs and symptoms, there's nothing to be ashamed about. There's nothing to be embarrassed about. Not your fault. You can get cancer anywhere. You can get benign tumours anywhere in your body.

And you're looking at a girl back in 1981, aged 11, she didn't tell her mum that she had started her periods for about two or three days, because she was so embarrassed. At one stage, because back in the early 80s we were so naïve, at one stage I actually thought, because we did a biology lesson on red and white blood cells. No word of a lie, aged 11, 1981, I honestly thought my red blood cells had burst and I was going to die.

00:20:56

CB

Oh, you poor thing. How traumatic. I don't think you're probably the only woman or young girl that went through that, that was terrified.

KB

Oh, but then in the back of my mind I thought, wait a minute, I think I could be having a period. I didn't tell my mum. She found me on the toilet crying my eyes out, I'm dying.

CB

Oh no, crikey.

KB

My mum went, oh, you've started your period. Out came a sanitary towel. But it goes back, in a way, to link it to having vagina cancer and cancer of the rectum, which is a pure back passage. It's still that 11-year-old girl, oh my god, I'm so embarrassed. Oh my god. And how it did make me feel… I promptly burst out crying when I was told that I had bowel cancer and it was up the rectum.

And after the operation, when they said the cancer had spread to the vagina, I promptly burst out crying again. The shame, the stigma, ashamed, embarrassed, mortified. I think that is the big word, mortified.

CB

And it's ridiculous, isn't it? Because you didn't do it to yourself. It's physiology. It's nothing that you could control.

KB

Yes, but it's still that element of, nobody's going to love me now. And it's still that, how am I going to word it? Am I going to tell people that I've got cancer up my bum, and I've got cancer in my vagina? Luckily, because I did my degree in sociology and I trained as a journalist, I have to put my sociology hat on, and my journalist hat on, and talk about it logically. But if you're talking to Karen the person, I still break down and cry. I still can't get my head around it. It's not one blow. It's two blows.

00:23:00

CB

Yes, in a crucial area, and sensitive. And a functional area, but it's a sexual area, as well.

KB

Absolutely. And don't forget, I had the hysterectomy before. I never talked about my hysterectomy until I got cancer, and then I gradually talked about it. Because back in 2005, hysterectomies, menopause weren't really talked about. And I was, what, only 44. So, all my love, marriage and babies dreams were gone out the window. It's only now that women are talking more about the menopause.

CB

Which is a good thing.

KB

Absolutely.

CB

Yes, it's a good thing. Definitely want to be covering that through Hidden Disabilities Sunflower. It's a huge, huge topic that we do need to talk about. So, you've got a colostomy bag. Having rectum cancer and vaginal cancer, obviously that's why you're having to have a colostomy bag. Are there any other effects that it's had on your body? You've mentioned your Barbie butt.

KB

Yes, the hysterectomy and the bowel cancer left my bladder weak. I have a weak bladder. Bearing in mind when you get to about 50, you naturally do start to have a weak bladder because of children, being older, putting weight on, you know what I mean. So, I'm on bladder tablets. And I'm not afraid to say that I have to use certain pads. I don't know if I can say the name. You know the name of the company.

00:24:56

CB

Yes, like TENA Lady.

KB

Yes. If they want a poster girl, I will happily be your poster girl.

CB

Yes, so if you're listening, TENA Lady…

KB

Yes, hi. If I can talk about vagina cancer, I can talk about TENA Ladies. Yes, I have to use a lot of TENA Ladies, especially when I go out and about, because I have a weak bladder. I think that's the most important thing, is the hysterectomy, the bowel cancer has left my bladder very weak. I did have a little operation about two years ago to tighten me all up, but I think I need some plumbing.

CB

Some recalibration.

KB

Oh, if you don't laugh about it, you're going to cry, so you might as well laugh.

CB

It is good to talk about it, though, because my aunty, she had bowel cancer. But thinking about it now, she also has a lot of issues with her bladder. And I think the initial operation she had was for her bladder. But it's next to each other, isn't it, I guess? I'm not a doctor, so I couldn't say it's next to each other. But it has had an impact.

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KB

And you had to do these awful things called pelvic floor exercises, which I'm just like, yes, right, when I tried to do it. But again, bladder problems are so embarrassing, aren't they? Your poo, your blood, your wee, embarrassing. And it shouldn't be. A lot of my friends in their 50s that are going through the menopause or have been diagnosed with cancer, they are absolutely like, oh my god…

00:26:57

CB

Hands in head.

KB

Why, in the 21st century, in 2023, are we still like this? It's almost like a Victorian approach, isn't it?

CB

Yes. Do you know, they do some great things for Stand up to Cancer on the television. And I like how they do it, because they'll have something that's really family-focused or light-hearted, and then they put these real-life people's videos in. But, again, there's obviously only so much time that they can do it, and it's a steppingstone for people to find out more.

But it is only the whole of the cancer and the person's journey, but you don't get to hear the nitty gritty. That's what we're talking about now, isn't it? It's the nitty gritty. And actually, by talking about the nitty gritty, we'll encourage people, as you say, let's reduce the stigma. And if you've got something that you think doesn't feel quite right, doesn't look right, just talk about it and go and get it checked out. The sooner you do it will have an impact for your outcome.

00:28:09

KB

Absolutely, Chantal. But what you have to remember, a lot of people are embarrassed to go to their doctors, especially men. That's why prostate cancer is so high. People are embarrassed to go to the doctor with anything that isn't your cough or cold. I think women with their breast and their sexual organs are like, I don't want to go to the doctor, it will go away. It's just me being anxious, it's nothing. And the longer you leave it, you can go from a stage 1, into a 2, into a 3.

And for the sake of your pride and dignity, just go to your doctor. They've seen it all before. And they will know immediately, like with me, my first GP thought that I just had piles. He didn't even examine me.

CB

Oh, dear.

KB

Piles, it's just piles. You're too young to get bowel cancer. Yes, but I have a history of bowel cancer in my family. No, no, go away, it's piles, here's your cream, off you trot. And the symptoms got worse and worse. So, January 2019, they got worse and worse. And then, March 2019, I couldn't control my bowels, I was in a lot of pain, I was losing weight. People were saying how dreadful I looked. I was trying to pass my sociology degree.

I went and saw the locum at the same surgery, and he said, let me examine your tummy, and he did. He says, okay, tell me what's been going on. And the next thing, he said, here's a letter, go up to Solihull Hospital. You need someone to look at this. I said, what's the matter with me? He said, something isn't right. He said, I felt something in your tummy.

So, I went on the bus to Solihull Hospital. They saw me there, and then they did a biopsy straight up the back passage. I've never been so embarrassed. I cried. You know, intrusion. I'm like, excuse me, young man. And then he said, I think it could be a tumour. It might be a benign, but I think it's more cancerous. And the next thing, the cancer nurse was talking to me, and then within about two or three weeks, I had the colonoscopy, which is the camera up the back passage. And there it was, stage 3 bowel cancer. I actually saw it on the screen. Is that in my body?

00:31:00

CB

What does it look like?

KB

It's like blobs, and it's got hairs and teeth, and disgusting. To me, it looked like a big giant monster. Well, several. But it might've been my brain overreacting. It looked horrible, because I saw the two nurses look at each other, and they're going, ooh. And the doctor, who was a lovely African doctor, said, well, that will have to come out. Who's picking you up tonight? My dad. I need to talk to you and your dad.

I could see it on the screen. I was like, that looks like aliens have got inside my body, yuck. Like Dr Who. And then obviously they gave me my cheese sandwich afterwards, and my bottle of Lucozade, because I had to starve before the colonoscopy. And then the African doctor went, my dad came, took us into a room, and said, you've got stage 3 bowel cancer.

CB

Your world must've just stopped.

00:32:06

KB

Yes, because it was Maundy Thursday 2019, just a few days before Easter. I had to go home, tell my mum and my sister. Mum burst out crying, because my granddad had bowel cancer. She said, your granddad had bowel cancer… Because they did say, you'd have to have a colostomy bag. Which I had to google, what is a colostomy bag? Oh, your grandad could never eat pickled onions. And that's how she kept going on about it.

CB

Oh my god, is that the shock? Is that why she kept focusing on that? She was in shock, pickled onions.

KB

Dad could never have pickled onions. I was like, well, okay. And then my Easter was just days of eating chocolate from a well-known Birmingham chocolate supplier, and just thinking, oh my god. And Mum crying, Dad in shock, my sister in shock. Mum every five minutes was hugging me, still going on about the pickled onions and granddad. It was awful.

CB

This is the thing. The whole family are affected, aren't they, by cancer. It's not just the patient. It's the whole family.

KB

And then I had to tell my friends. And then I had to tell university, and my lecturers were just so kind and supportive, and the disability team at the university. Everybody was so supportive. My church were very kind and supportive. And that's when you see people in society at their very best.

CB

At the beginning, we were talking about chemotherapy and radiation. You've had radiation, as well, haven't you?

00:34:05

KB

Yes, radiotherapy.

CB

Yes, radiotherapy. So, I think it's also another thing that's not spoken about so much, is the lasting impact that that can have on a person's body. Can you just give me some insight into what effect that's had on your body?

KB

Yes, radiotherapy is not nice. I had it for six weeks, five times a week. So, Monday, Tuesday, Wednesday, Thursday, Friday, double dosed on Friday. Radiotherapy, it burns you places you didn't know you could get burnt. Ouch.

CB

Ouch.

KB

I used to like having my radiotherapy, because I used to like watching the sails go round.

CB

Can you describe when you're having radiotherapy? You go into a room, it's not an injection.

KB

You go into a room. At the QE Hospital in Birmingham, where I had mine, there were all flowers on the wall and flowers on the ceiling. It was pretty tranquil. And then you have to lie down, and they put markers on your body already where the radiotherapy has to target. So, I used to call it my complementary tattoos off the NHS. And I've still got them now. They will never wash off. Like little dots.

00:35:36

And they used to line you up, so you're flat on your back, and they line up the machine, and then they all have to leave the room. And then this machine, it's like a sail. It targets the area where the cancer is to reduce the tumours for the operation. So, I used to watch this sail go round, thinking that I was strapped to a windmill, going round and round in the countryside with all these flowers around me. And it was the most therapeutic experience of my life.

CB

Oh, really?

KB

I loved it. I know some women and men hated it, and I was quite happy watching the sail go round for about seven minutes. And that's all it is. There's nothing to be scared of radiotherapy. You've got to get yourself in the right mindset, so practise mindfulness, watch the flowers, and watch the sail, and pretend you're on a windmill in the countryside strapped to the sail going round and round.

Yes, it's okay, because you know that the radiotherapy is shrinking the tumour so they can operate. It did burn me in places I didn't think you could get burnt. Because I was a young woman, the nurse gave me this thing. And I am like, no way, I am not using that. I'm quite happy. It was something that you buy in Anne Summers, and we'll leave it at that, because it can shrink your womanhood. I didn't use it. I'm like, no. It's that embarrassment. So, it was in the drawer.

CB

It was given as a Christmas present to someone in a Secret Santa.

KB

This is an NHS one, so it wasn't very pretty to look at. But again, it was that, oh my god, you can't do this. This is naughty. But she said, sometimes it does shrink, sometimes it doesn't. I was okay. Yes, but radiotherapy is okay. And I used to always have double dose on Friday, so I'd be practically crawling down the hospital corridor. And Friday was always taxi day, because I was so tired having the radiotherapy twice, that I used to treat myself to a taxi ride home, as opposed to slogging it on the bus.

00:38:10

CB

That's another thing, I think, that we maybe don't consider, is people having treatment, and it's the journey there, and the journey back, and the exhaustion, and the pain or sickness that somebody might be feeling, but then the extents of getting there and getting back. You just want to be whisked away in a warm, comfortable car, don't you, as opposed to having to battle with public transport.

KB

Yes. It was tough, because I used to walk up to Acocks Green Village, catch the bus, go to the hospital for my radiotherapy, and then get the bus back, and then walk through the Green, and get home. It was literally a full day out.

CB

Bless you. So, radiation, does that deplete your immunity, or is it the chemotherapy that eradicates your immunity?

KB

I'm not medically trained, and I'm not that brilliant on human biology stuff and biology stuff. I think it was more the chemotherapy and more the cancer. But the chemotherapy was brutal. Radiotherapy, I actually quite enjoyed, because I found it quite therapeutic. And if they said to me, you've got to have more radiotherapy, I'd be like, ooh, yes please. And because I live in Cheltenham now, we're only a 20-minute walk to the hospital. That'd be nice. So, I'd be like, yay.

00:39:55

Chemotherapy, I had it before I had my chemotherapy. It was probably two months after surgery. I was scared of the chemotherapy chair. I was petrified of it. And at one stage I said, I don't want chemotherapy. Is my hair going to fall out? No, Karen, your chemotherapy drug does not make your hair fall out.

I think it's called FOLFOX, which is like the stable workhouse chemotherapy drug they give you for bowel cancer. No, Karen, your hair is… And she must have said it several times. As you can see, I've got quite long hair. I know it's really vain, but my hair's my pride and glory. So, we ruled out that it wouldn't affect my hair.

And then, secondly, we had to make friends with the chemotherapy chair before treatment. So, Laura, my chemo nurse, said, okay, let's go into the ward. I want you just to sit in the chair for a half hour, and you can move the chair up and down, because it was a recliner. She says, just sit in the chair and make friends with the chair. She says, there's the television, so you can watch the telly.

So, for about half an hour I was just sitting there in the chair, getting used to it, seeing what was going on in the ward with the patients and the nursing staff. And I gradually thought, well, this chair is going to save my life. Because if I don't have chemotherapy, the chances are that cancer will come back, and I won't be so lucky next time. So, I made friends with the chemotherapy chair, and then I had six months of chemotherapy, which is usually like half a day of having treatments.

CB

It's a long time of sitting there, isn't it?

00:41:50

KB

Yes, about four to five hours. Because I could take the chemo drugs, they had to put a vein in my arm. So, I had about four or five hours of chemotherapy every two weeks. And then I would go home, and I'd have mobile chemotherapy. So, there's a flask of chemotherapy, which is like a balloon inside the flask. They attach it to the hook of my jeans, and then the chemotherapy runs from the flask via the tubes into my arm, which meant I could have chemotherapy at home.

And it would still be working whilst I was sleeping, watching the telly, eating my tea, in the back garden reading my book. I could even have a bath. If I wrapped this arm all up in clingfilm and had my arm dangling out, I could still have a bath.

CB

So, how many hours a day, then, is that going in to? You've got four hours in hospital…

KB

Mobile chemotherapy is 24/7. In the flask, there's a balloon, and you have to wait until the balloon goes right the way down, and that indicates that the chemotherapy is finished. It's brilliant. It was like a science lesson in itself. Otherwise, it meant I would've had to have been in hospital, every two weeks I would've been in hospital for three or four days.

00:43:21

CB

Okay, so it's allowed you to stay in the comfort of your own home.

KB

Unless it went wrong, like it got blocked, or it caused a sepsis rash, or they thought I might have a clot, I had to go straight back into hospital. And during lockdown, there was hardly anyone in hospital, unless it was the really poorly COVID… So, I used to have a little private room, and it was like being treated like a VIP. It was brilliant. I'll never experience that again, but it was good.

CB

Well, you are a VIP. I mean, crikey, that's an awful lot to go through. So, you used to have a career in travel and aviation. You've been really open with how your health journey has been. How has it impacted your career?

KB

Oh, I'm going to cry Going through the airport security with colostomy bags, that in itself is a whole new episode. The horror stories I hear, just because a person wears a colostomy bag.

My life is now in the UK when it comes to travelling. I did, as a journalist, after I did my main journalism qualification, I did do travel and tourism, journalism, and travel writing, and travel photography. Which is great, because I can just concentrate on the UK. As long as I don't fly and don't go abroad, I'm okay. But it is restricting. Every time I see a plane in the sky, I go to an airport, I get emotional.

CB

You've got no choice in it. It's been thrust upon you.

00:45:46

KB

Yes. Thank god I did 30 years in travel and tourism and aviation.

CB

So, again, you're spinning it round to the positive. So, what are your life goals and ambitions now? Presumably to do with the Pageant Queen?

KB

Oh, my life goals, I fulfilled them very quickly, because I've only been doing pageants ten months. Pageant Queen three times over, and a Princess, as well. I feel like the Royal Family. Yes, modelling is great, I enjoy that. I think the next thing I want to do is, I'm doing a course in June, and it's on how to write your autobiography.

CB

That's good.

KB

The next is the book.

CB

Yes, that'd be great.

KB

I think that's my big thing for next year. And if my cancer does come back, or the brain tumour, I have to have an operation or radiotherapy, I can sit and do it on the ward and at home.

CB

That's a really good idea.

00:47:01

KB

So, I'm doing the course in June. It's for one month. So, I think to get the book out, and because I'm Karen, I would love the stage musical.

CB

Why not?

KB

Hello, Gary Barlow, Karen the Musical. Cracking. All songs by Take That. I've been offered the chance to maybe do some community radio, which I'm very happy about doing.

CB

Oh, yes, I think that would be fantastic for you. You come across really well. Your conversation and your humour is really endearing, so definitely go for that. You mentioned about the colostomy bag earlier on, and using in airports, in security. And it kind of brings me on to a question I wanted to ask you about the Sunflower.

We know a lot of Sunflower wearers who have a stoma and wear bags find the Sunflower is really beneficial at airports because of the pat-down and security process, that they're able to… Obviously, they have to go through security, but it's done in a different way and in a much more compassionate approach to that. What are your thoughts about the Sunflower? Do you wear it?

KB

I do. Excuse me one moment. I've got a bus pass because I tick so many disabilities and have so many problems with mobility and balance. And because of the brain tumour, I can't drive. Yay.

CB

Karen's holding up her green Sunflower lanyard.

KB

There's my picture. Yes, I wear this all the time. Which brings me on to another thing that I'd like to do, is to be a Sunflower Friend and talk about hidden disabilities, invisible illnesses, probably from a travel and tourism perspective. About the toilets, don't get me started on toilets. Disability toilets, half the general population think, unless you have a wheelchair or a walking stick, you cannot use the disabled toilet. Don't get me started on that.

00:49:33

CB

It's a whole other podcast.

KB

I know when I wear my Sunflower lanyard, when I go on the coach or on the trains, they're so kind. National Express are so kind. The train companies are very kind. I can be standing there at the train station like, where's the platform, where am I going, and they're there, and they will help me with my luggage, make sure I'm on the right platform, the right train. They will help me with my suitcase. And the general public, I would say probably the under 50s, especially younger people, they get it, and they will help me.

CB

Good.

KB

I've had a few people that have got these lanyards on and go, oh, you've got one as well. What's wrong with you? It's like a little fan club. Oh, I love being part of this club. I go to Gloucester Adult Education Centre, and I would say nearly all of us have got one of these.

CB

Really? That's interesting.

KB

It's funny. Especially when you make a recipe that's got lots of beans in it, we all suffer the consequences the next day. And that's why I think it's important with this Sunflower scheme, we're all equal.

00:51:05

CB

Where would you suggest someone facing what you have been through, and are currently going through, where would you suggest that they turn to for support?

KB

The most important thing is, you're not alone. Don't sit there in the house and feel you're the only one, because you're not. For support, I would turn to the Sunflower scheme and meet fellow people, like yourself, that have had cancer, brain tumours, invisible illnesses.

Macmillan Cancer Support are brilliant. They do lots of exercise classes, counselling, buddy networks, one-to-ones. You can even go to the gym and they will help you get fit again, and build up a lot of the… I'm not very good with… You know when you lose a lot of your muscle. Muscle wastage. They're very good with that. And you do lose a lot of muscle wastage with cancer.

So, Macmillan Cancer Support, any of the cancer charities, whatever cancer you've had, there's a charity that will look after you. So, for me, it's Bowel Cancer UK, Colostomy UK, and there's loads of very small online forums where you can talk to people that wear a colostomy bag. And believe me, some of the conversations online are…

But you're united. And, oh my god, I have poo disasters, someone else does. Someone else has a stoma hole that keeps blistering. So, you realise that all the problems you have with your stoma and your bowels, someone else has. So, online forum groups, cancer charities. I think your family and friends, your local church.

00:53:16

And I would say adult education centres, because a lot of the courses are free. It gets you out of the house. You're learning new skills. And you're meeting people whose parade got rained on, too. I think that's the nicest way to say it. Their parade got rained on, too, and they just want to be part of that parade again, and walk out in the sunshine and say, hey, this is me, I've had cancer, I've come out the other end, and now I'm marching united with all the other cancer survivors in the world.

One big parade for all the cancer survivors in the world, and bring in the brain tumour survivors, and everyone else, the hysterectomy survivors. Because we don't celebrate, and like a Pride parade, we should have one for cancer patients and brain tumour patients, etc., every year. But we don't. We should.

CB

Yes, definitely, because you're survivors and you've had a tough road to walk down, or climb up, even. So, absolutely, I think that's a brilliant idea, great suggestion. And thank you for the other suggestions, as well. It's really useful advice. And Karen, thank you so much for giving me your time today. It's been brilliant.

00:54:42

KB

Oh, thank you very much. And I just want to end on, when you get cancer, or a brain tumour, or you have to have a hysterectomy, whatever it is, it's not the end. It's just the beginning of a brand-new chapter in your life. And it's full of the most amazing adventures, opportunities, and travels. And you get to meet people just like you. So, it's not the end. It's just the beginning.

CB

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VO

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00:56:15