

Bowel and lung cancer, stoma and dialysis with Gemma Savory

Speaker 1:

Welcome to the Sunflower Conversations, where we explore the hidden disability sunflower, and its role in supporting people with hidden disabilities.

Chantal Boyle:

Welcome to the Sunflower Conversations with me, Chantal. Today, I'm going to be having a chat with Gemma Savory. Gemma has been living with bowel cancer for the past 10 years. Gemma, welcome. Can I start off by asking you, how old were you when you were diagnosed with bowel cancer?

Gemma Savory:

I was 30. I was pretty young to have bowel cancer, but it came after, well, I probably spent the best part of nine months or so going to and from my GP with various symptoms, some that obviously related to what we would know as normal kind of bowel cancer symptoms, but there were other symptoms as well, which weren't the kind of regular, which maybe threw them off a bit, but it was a long process to get to a point where I was actually getting any tests done. So it kind of felt a bit more of a relief to find out there was something wrong by that point, even though obviously it was a pretty big shock that it was cancer.

Chantal Boyle:

Yeah, I can imagine. So how did those symptoms begin?

Gemma Savory:

I probably began with, I was feeling quite tired, run down all the time, which probably wasn't too kind of concerning or uncommon because I also had kidney issues as well, so they put all that down to that. And then I started experiencing random bleeding in between my periods. So then I was going to the doctors and it was like, oh, it's probably a hormone issue, let's see if it will settle down. It could be that you stressed. And then I started experiencing stomach pain, back pain. I was getting constipated a lot. I was losing a lot of weight. By the time I got diagnosed, I'd lost two and a half stone in a matter of those months.

Chantal Boyle:

That's a lot.

Gemma Savory:

A lot. And I wasn't very big to begin with. I think when they weighed me, I was about five and a half stone.

Chantal Boyle:

Oh my goodness. You must have been struggling to put one foot in front of the other by this stage.

Gemma Savory:

Yeah, I was feeling pretty unwell. I knew something had to be done. I got diagnosed in October, but when we went away on holiday in the summer with my family, I really struggled. I struggled to get around. I couldn't eat because I felt so full and bloated all the time. I was feeling pretty unwell. And then I was actually referred to the women's hospital in Birmingham, as they thought it was probably a gynecology issue, so they examined me. They couldn't find anything wrong, but they sent me for a colposcopy anyway. Had a colposcopy that came back fine.

Chantal Boyle:

Oh, is a colposcopy, if you don't mind me asking, is this up through your vagina?

Gemma Savory:

Yeah. It's a camera to check your cervix basically to see if there's any changes that they can see on the cervix. So I was kind of sent back for another appointment with the consultant, which was basically to discharge me from their care because they couldn't find anything. And then by this point I could actually feel a lump internally. And I begged them again, I was like, please, please, just please check again. They did and this time they did actually find the lump, which they said before was probably a cyst.

Chantal Boyle:

Right.

Gemma Savory:

Sounds pretty gross. But it did actually, when they examined me, did actually burst and there was a big gush of blood, so that worried them. So then they sent me straight away for a second colposcopy, literally that day. The air in the room was very different. They inserted the camera, the room went very quiet. The doctor just said, oh, there's something there that we need to take a biopsy from. So I had a biopsy there and then, and then they said, come back tomorrow for the results.

Chantal Boyle:

They never say come back tomorrow, do they?

Gemma Savory:

Yeah.

Chantal Boyle:

Normally in two weeks time, so that must have had alarm bells ringing.

Gemma Savory:

Yeah. And also they did say, there's a possibility it could be cancer. And you think when they say it's a possibility, you know that they're pretty much a hundred percent sure that's the case because they wouldn't have mentioned that otherwise. So I just remember going home from that appointment, literally just kind of zombie into the lift and my husband was like, oh, what did they say? And I just went, oh, they said they think it could be cancer.

Chantal Boyle:

Oh gosh.

Gemma Savory:

And then that was it, we didn't really talk about it again. It was a very sleepless night. And then we went back the next day. I can literally remember the hour, the minute, the day and everything. And they said, yes, you've got cancer, but they didn't know what it was, which type of cancer it was at that stage.

Chantal Boyle:

I intrigued though. So all of this investigation has been done through your cervix, not from your bowel.

Gemma Savory:

Yeah, because the tumor in my bowel had gotten so large, it had burst through my bowel and it had started to break through into the back of my vagina wall.

Chantal Boyle:

I see.

Gemma Savory:

That's what they found originally. So at that point they didn't know whether it was cervical cancer or vaginal cancer or what... So they sent me some more tests. They sent me for an MRI and a CT scan. And then that's when the tumor in my bowel was found and it was, what did they say? I think it was eight inches long in my bowel. It was really big. And as I said, it had already started to break through.

Chantal Boyle:

Were they able to say to you, well, it probably had started growing X years, X months ago for the time when they actually were able to diagnose it or is it impossible to know how long it's been there?

Gemma Savory:

My bowel surgeon said that I probably had likely had it for up to five years. It does show actually how late symptoms of bowel cancer can start before you get diagnosed. But I think going through the process and having to really beg and push at every stage to get even tests. And it was purely based on my age, I was told to many times by my GP that you're too young to have anything wrong. It's stress, it's anxiety, it's hormonal.

Chantal Boyle:

Does that make you feel like you're going insane? with you having to keep going back and thinking this isn't right, this isn't right, I know it's not right.

Gemma Savory:

You feel stupid and you do feel a bit of a nuisance.

Chantal Boyle:

Yeah.

Gemma Savory:

But I'm glad that I did push some answers, even though it was diagnosed quite late stage, it still could have been so much worse I guess if I hadn't pushed hard for those answers.

Chantal Boyle:

So you are currently NED and is that no evidence of disease? Is that what that means? Have I got the acronym correct?

Gemma Savory:

Yeah, that's right. Because my cancer did spread to stage four... Because after the original diagnosis and treatment, it did come back a year later in my lungs. I will always be classed a bowel cancer patient. I will never achieve what they call remission as such, because they are always at stage four, it's always likely to come back at some point, but at the moment I'm in the best place that I can be, which is Ned or NED, no evidence of a disease.

Chantal Boyle:

That's good. That's good. And so what has your journey been like? I mean, you've already alluded to having to really fight your corner and what it was like when you went home and told your husband and the sleepless night. But can you share with us a little bit more about your journey and how many operations and treatments you've had, because you've also said that it spread into your lungs as well?

Gemma Savory:

Yeah, to be fair, once I was under hospital care, I've had such amazing care. I was treated at the Queen Elizabeth Hospital in Birmingham. The first thing that they did was they decided to do an end colostomy, which was to make me more comfortable. Initially it would allow me to be able to eat because it would bypass the tumor. Also, because the next treatment was chemo-radiation, so a combination of chemotherapy and radiotherapy, it meant that I would be more comfortable having a colostomy than going through treatment without it because having your bum fried in radiotherapy is very painful. So it was five weeks of radiotherapy plus chemo on top of that to shrink the tumor down so that it could be operated on. So after I had that, I had to wait a few months for the... Because after you've had radiotherapy, the treatment continues to work for a few months, so they had to wait for that.

Gemma Savory:

And then I had my second bowel surgery, which was called an abdominal perineal resection. And mine was with a myocutaneous flap reconstruction as well. So it was a pretty massive surgery. It involved basically... So they removed the rest of the valve that was underneath my stoma. They removed my rectum, anus. They removed the back wall of my vagina. They cut all the muscles out on the right hand side of my body plus a flap of skin. And they used that to reconstruct my vagina and the rest of the area down there to make it... So there's not a gaping hole left, basically. It was pretty brutal.

Chantal Boyle:

This is really, really intrusive and brutal, isn't it? I mean, brutal is the word that we need to use here, isn't it?

Gemma Savory:

Yeah, it was nine days of intensive care after that and another two weeks in a ward. That was probably my hardest recovery physically and mentally, because basically I described myself as a patchwork doll. I had a scar that ran from my ribs basically, off down the muscle and skin graft that they created isn't the prettiest to look at. Obviously I've got my stoma bag on top of that. So I didn't feel very pretty after that operation.

Chantal Boyle:

And I'd imagine when you have been in such a serious amount of work done to you and not being able to move for such a long time, you're stuck there with your thoughts and the pain aren't you?

Gemma Savory:

Yeah and it was a very difficult recovery. The days in intensive care, I was kept half sedated for the first few days and I had an epidural in my back, which meant that I couldn't feel my legs. I also, I wasn't allowed to lie on my back because of the surgery that I'd had. So every two hours nurses would have to come and physically move me from side to side and I was stuck like that for basically about a week until they finally weaned everything down. And then the first day of trying to get out of bed and walk was... I was just like Bambi on ice. I didn't have my legs.

Chantal Boyle:

Yeah. Well also you've got no stomach muscles.

Gemma Savory:

Yeah.

Chantal Boyle:

As well.

Gemma Savory:

Yeah, don't have them. Yeah, you don't have the core strength to hold yourself up very well.

Chantal Boyle:

Yeah.

Gemma Savory:

Not to mention all the drips and drains. I had drains in either side of my hips. I had one coming from my bottom, which is really uncomfortable. It was a tough recovery.

Chantal Boyle:

Yeah, it sounds really, really tough. You're a tough cookie.

Gemma Savory:

Yeah, I think it took probably about 12 months to fully recover. I wasn't able to physically sit down for about three months. So it was kind of awkwardly trying to go outside or if I had to go out or sit anywhere, I was kind of trying to shuffle from one bum cheek to the other.

Chantal Boyle:

Oh bless you.

Chantal Boyle:

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Chantal Boyle:

And you've had chemotherapy, you mentioned radiotherapy. What is the effect of chemotherapy like?

Gemma Savory:

It's hard work. The first sort of chemo I had, had something called 5FU, it did make me feel quite nauseous, quite tired. The first time around I had it, had kind of post-chemo [inaudible 00:14:29] from my surgery for about... Had it weekly for about nine months. And at that point as well, just for financial reasons, I went back to work and it was kind of hard. I'd have chemo on the Friday, I'd feel ill all weekend, ready to go back to work again on the Monday. But it is the only way to get by, really.

Gemma Savory:

The second time around, after I was diagnosed with the lung mets. I had something called FOLFOX, which is a mixture of 5FU plus another chemotherapy called Oxaliplatin. That was harder. It was tougher because that treatment that I needed, I mentioned earlier that I kidney issues. It meant the drug is nephrotoxic, so it meant that because of my low kidney function, I got forced onto dialysis and starting dialysis and chemotherapy on the same day, it was rough. It was rough. But weirdly, they've

worked out that my dialysis treatment was causing two lots of spikes, so I was getting hit by side effects, twice as hard.

Chantal Boyle:

Oh, it was processing it through your system double or too quick.

Gemma Savory:

Yeah, because the dialysis was just washing it around. I had really serious nausea sickness on that one because the first few days you're given steroids to help you with the side effects. And then the day when you stopped the steroids, you'd be kind of hit like a brick wall where it would literally just hit you all at once. And I don't know, the only way I could describe the nausea was everything you looked at, felt, touched, smelt, just made you feel like you wanted to be sick. And the only way to cope with it was literally just lie in a dark room and wait for it to pass, which usually took about three days.

Chantal Boyle:

That sounds horrendous.

Gemma Savory:

Yeah.

Chantal Boyle:

Horrendous.

Gemma Savory:

Yeah.

Chantal Boyle:

And then you have to go again and have it the next week?

Gemma Savory:

With that one, I had it every two weeks, I think.

Chantal Boyle:

Every two weeks.

Gemma Savory:

Then they tried to push it out every three weeks because I then also developed peripheral neuropathy, in my hands and feet, which I've still got. So basically nerve damage in my hands and feet.

Chantal Boyle:

And that's an effect of the chemotherapy?

Gemma Savory:

Yeah, that was specifically over the oxaliplatin which is a well known side effect.

Chantal Boyle:

Have you been involved in your treatment plan? How many years now have you been a cancer patient?

Gemma Savory:

Roughly eight years.

Chantal Boyle:

Yeah so over the years, have you become sort of quite au fait with different drugs and treatments and do you have a hand in what they plan for you or do you leave it a hundred percent to the experts?

Gemma Savory:

Yeah. I mean, you kind of do put your life in their hands, really. If they tell you that they think that a certain treatment would be good or would work, then I've always gone with it. Lots of people are different. I never really heavily researched all of the options available to me. I knew they were limited anyway, being a dialysis patient as well. And at the moment, their thoughts are very much, for as long as possible they want to keep me away from chemotherapies or chemical treatments because of the situation with my kidneys. So most of my treatment in the last two years has been just wait and watch to see whether anything grows and then if anything happens, then we'll revisit or look. So I know for me, they're more happier, they're keen on surgical treatments rather than...

Chantal Boyle:

Okay. So with that in mind, you're a dialysis patient now, does that mean that you are waiting for a kidney transplant?

Gemma Savory:

No, unfortunately, because I'm a cancer patient, I'm ineligible for a trans.

Chantal Boyle:

Sorry to hear that.

Gemma Savory:

No, it's fine. So dialysis is a lifelong treatment for me now.

Chantal Boyle:

Do you have that daily or...

Gemma Savory:

Every other day.

Chantal Boyle:

Every other day. Can you do that at home or do you have to go somewhere?

Gemma Savory:

I do, do that at home now. I've got a hemodialysis machine set up upstairs as the hospital. They came and got a machine installed for me. And myself and my husband basically trained as dialysis nurses.

Chantal Boyle:

And then if you were to travel away from home, can you take that with you?

Gemma Savory:

No, they're huge. I have to go into a hospital or a center, a dialysis unit while I'm on holiday, if I do go away.

Chantal Boyle:

Okay, so is it UK based trips if you go anywhere?

Gemma Savory:

No, we have been to Majorca. We've done it in Majorca.

Chantal Boyle:

Okay, great.

Gemma Savory:

So it takes a lot of planning. You have to have a lot of tests before you go away to make sure that you're safe. I mean, it went pretty smoothly. There was a bit of a language barrier. I was told that all the nurses there do speak English, but nobody did.

Chantal Boyle:

Google translate.

Gemma Savory:

Yeah.

Chantal Boyle:

It's quite a serious subject if you're relying on Google translate for, isn't it? Has it translated this correctly?

Gemma Savory:

It is if you're not feeling very well, because there's a very fine balance thing there.

Chantal Boyle:

Yeah and you've also got a stoma. Was that difficult for you to get used to or was it as everything else that you had, it was just another thing that you just had?

Gemma Savory:

In terms of practically, how it functions and whatever, I got used to that pretty quickly. Pretty much the day I had the surgery, I was shown how to change and care and look after my stoma so that I was self-sufficient straight away. I've been lucky in that the majority of the time I don't have any issues with it. There have been the occasional kind of oops moment. The mental side of having that change to your body, again, is not the prettiest thing to look at. It's not something you'd aspire to have.

Chantal Boyle:

Yeah. If you don't mind me asking you this, it's quite personal, but the red valve, I guess, is that part of your body or is that a plastic connection?

Gemma Savory:

No, that's your actual bowel.

Chantal Boyle:

That's your actual bowel and it's not sore on that red bit?

Gemma Savory:

No, no. There's no nerve endings in the bowel. You can feel sensations like tugging sensations or something like that if it's not working. Obviously the skin that surrounds it can get quite sore occasionally. That's gently the only kind of pain you feel. The actual stoma itself, there is no pain. It is literally your bowel that they see through a hole that they've made and then they flip it back on itself and sew it to your body. So that's why it looks the way it does.

Chantal Boyle:

I mean, it is incredible, isn't it? You think about everything that you've had done, which is why you are able to sit here and chat with me today and share your very, very, very personal story. And thank you for being so candid with the treatments and the operations that you've had. I think it's important that if people are comfortable to share, that we do share it so that we can raise awareness because it is very much a non-visible disability. There's no way you'd guess by looking at you that you've been through all of this.

Gemma Savory:

Yeah and it's very much the realities of having bowel cancer and the treatments that are available to most NHS patients or whatever. This is the reality and this... And it's what I'm living with. I mean, my situation is probably not standard textbook because of the other chronic illnesses that I do have alongside of it, but for most people diagnosed with bowel cancer, this is what it is.

Chantal Boyle:

Yeah and you are working, aren't you?

Gemma Savory:

Yeah, I do. I work part-time as a freelance copywriter, mostly for the blood and bowel community. And I love doing that. It's a great way for me to meet other people who are perhaps suffering with bladder and bowel conditions and to offer up my experience and my advice.

Chantal Boyle:

Yeah, it's a perfect fit.

Chantal Boyle:

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Chantal Boyle:

So do you wear the hidden disability sunflower? And if you do, what situations do you tend to wear it and why?

Gemma Savory:

Yeah, when I went away on holiday actually. I wore it through the airport and I was shocked at how well it worked, to be honest.

Chantal Boyle:

Really?

Gemma Savory:

Yeah, I wasn't really expecting anything to come of it at that time. I think they were still relatively new, not that many people knew about it. So I wondered whether anybody would recognize it at all. But as soon as I got to airport security, I got called over and I was like, oh God, what's happening? What's going on? And all they did was they opened up another checkout and let me go straight through. And I was like, oh. So I was watching everybody else who was [inaudible 00:24:23] miles and I was just [inaudible 00:24:24].

Gemma Savory:

When you go through the scanner, they obviously noticed that something popped up on the scanner in my bag, they always notice. One security guy went to pat me down and checked me out. And then another security, she was a woman, actually came up and said, don't, she's got the lanyard on and they just let me go. So it's like, okay. And then again, getting on the plane, I was asked if I needed any help, if I was okay. Even once I got to Majorca, I got to Spain, I didn't think at all they would know for one second, they knew what it was. Again, I got pulled to one side and I opened up another security just for me to go through, so it was so quick, so easy.

Chantal Boyle:

Yeah and everything that you have to contend with your health and maintaining your dialysis and everything else. I mean, that must make such a difference to having a good holiday.

Gemma Savory:

Yeah, it's definitely a nice perk and it does help, especially if you... I suffer from fatigue quite badly, so standing in queues for hours is really not ideal. So yeah it's brilliant

Chantal Boyle:

Through your journey, are there charities or support groups that you've turned to?

Gemma Savory:

Yeah, initially I was in contact a lot with Bowel Cancer UK. They were really great. They helped me through it. They put me in contact with a lot of other people with bowel cancer. And then again on social media, there's a big community of us out there obviously made more famous now with Deborah James and Bowel Babe and then obviously through our own bladder and bowel community, everyone there has been a great support. I actually run the Facebook group. We've got 18,000 members now.

Chantal Boyle:

Wow.

Gemma Savory:

So there's a lot of people out there with bladder and bowel conditions who want other people to chat and talk with, and that's what we are able to offer.

Chantal Boyle:

We'll include a link to that in the show notes for anybody who would like to join or become part of the community for a bit of support.

Gemma Savory:

We are all a friendly bunch. There's nobody there who will criticize you for your illness or make you feel bad. Everybody's very supportive because they're all going through the same. And that's what's so great about it, to have that many people out there who are offering support to other people.

Chantal Boyle:

So as we come to a close of our lovely chat today, what are the potential signs of bowel cancer that people need to look out for?

Gemma Savory:

Yeah, so the most obvious signs are experiencing any stomach pain. If you can feel any visible lumps or bumps around your stomach, any bleeding, like when you're

bleeding when you go to the toilet or any abnormal bleeding, constipation, or having diarrhea, any kind of changing bowel symptoms, kind of like bowel movements that are abnormal for you and that last longer than three weeks is a red flag. Tiredness, feeling just generally run down, losing weight. Those are all kind of the big red flags of bowel cancer. So if you do experience any of those symptoms, then it's important to go to your GP. And remember that you're never too young to have bowel cancer. So if you feel that there's something wrong with your body, don't get fobbed off, you need to keep going back repeatedly until you get answers, then do that.

Chantal Boyle:

Thank you. You've put that so succinctly. And I think Gemma's story is testament to, if you feel there's something not right, just keep going back. So I want to thank you for your time today Gemma, it's been an absolute pleasure to chat with you, and it's great to see how well you are looking and you are obviously working and supporting so many more people within the bowel cancer community. So thanks for your time because you're obviously a very busy lady.

Gemma Savory:

No, thank you. It's been great to talk.

Speaker 1:

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