Series 3, Episode 2: Cancer and fertility

Angie Greaves: What do you do if you're told your cancer treatment will make you infertile?

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Angie: Hello, I'm Angie Greaves. Welcome back to Talking Cancer, a Macmillan Cancer Support podcast sponsored by Boots, where I meet real people and have conversations about living with cancer. I'll also be meeting some of the experts from Macmillan and Boots who can share their knowledge and guidance for anybody affected by cancer. Now, in this episode, we're talking cancer with Krista.

Krista: I was tested for everything. At the end of that, they diagnosed me with a very rare form of blood cancer.

Angie: In the middle of the coronavirus pandemic, Krista received a fateful phone call that would change her life.

Krista: I really didn't hear anything that went through that call apart from the word cancer which was like a foghorn.

Angie: Still coming to terms with her diagnosis and facing treatment at home, Krista had a huge decision to make.

Krista: Whether I started home chemo or if I went in and started the fertility process.

Angie: We'll also be hearing from Azmina Rose, Macmillan cancer support and information specialist for some expert guidance about cancer and fertility.

Azmina Rose: Well, Angie, different types of cancer treatment can affect fertility in different ways.

Angie: We're Macmillan and we're Talking Cancer. Good morning, Krista. Welcome. Thank you so much for talking to us today. Can you tell us a bit about what your life was like before your cancer diagnosis?

Krista: Wow, I can. Before the cancer diagnosis, I was living as a health and lifestyle coach. I was living in Australia, Sydney. I was very fit and healthy, I was a yoga instructor. I taught yoga therapy. I ate very well. I was very active. I was a pseudo athlete, so I did adventure racing. I was always out kayaking or running in the bush or being adventurous. I love to travel, love adventure. I was running my own business, had my own clinic with my own clients. Life was pretty, pretty good. I was on track and on purpose. I was looking at basically deciding to settle down and create my own family and start to live the next part of the dream. Then I actually came back to the UK for family reasons back in 2019 before the inevitable happened.

Angie: The plan, I was going to say it, the plan didn't quite work out as you had envisaged because you go to your GP July 2019, yes?

Krista: Yes. I can look at it from a funny perspective now. I had come back to England and I had joined a company. I was a contractor for them and I was working as a director producing a coaching education diploma for the UK to teach health coaches. I head out one day to go to an event and try and put a pair of heels on and I couldn't balance in them. I put it down to living a life in Australia barefoot, flip-flops, and just out of practice of wearing heels, literally. I never looked into it any further. Then I went to the GP because I was starting to get fatigued. I was taking the dog for a walk and I would come back and I'd just be so tired. Again, I put that down to moving countries, setting up in one place and just having a lot of pressure on me, so I just didn't really think anything of it at all.

Angie: When you were diagnosed, this was March 2020, what was the space like in between July 2019 and March 2020? Can you just give me a quick precis of that and then we'll go into the diagnosis.

Krista: March 2020, I actually was sent to hospital for investigation because they still didn't know what was wrong with me. I actually got an official diagnosis. I got wrongly diagnosed to start with with something else. I actually got officially diagnosed in May 2020. Literally from July moving forward, I was getting a lot more fatigue, and I was, again, I ended up having migraines. This was probably about August time. I never suffered migraines. They were so bad that I was recommended to go to A&E. When I went to A&E, they worked out that I literally couldn't stand on my tiptoes or go back on my heels. Now, for someone that does yoga and is constantly standing in warrior pose or tree pose, if you don't know what that is, they are balance poses where you stand on your tiptoes or back on your heels, it was the most bizarre thing. My brain couldn't understand why this was happening or occurring. Literally from that point through to March, I was tested for everything. At the end of that, they misdiagnosed me with something called CIPD, which is an autoimmune disease. I went away and I was treated for that. Then basically, a couple of weeks later, the treatment wasn't working and I was still getting worse. Then in May, I actually got a call from Cambridge Hospital from my neurologist and he gave me the news that, actually, it wasn't a CIPD, it was actually a very rare form of blood disease, blood cancer.

Angie: Krista, being diagnosed over the phone in the middle of the first lockdown in England, how was that for you?

Krista: It was surreal. It was very surreal. It wasn't like you go in and you sit into a doctor's office and they sit down and give you lots of information. It was a very short call. I really didn't hear anything that went through that call apart from the word cancer, which was like a foghorn. It was the last thing that I was expecting. I didn't expect to be coming back with a diagnosis of cancer. It literally took all of 20 minutes to have that phone conversation. A lot of it was my neurologist being very apologetic. I wasn't expecting anything because I had no idea what questions to ask, so I had no idea what this diagnosis was, how it affected me or anything. I went away. I remember having the conversation, I was literally sitting outside in the garden. The birds were cheeping, the sun was shining and I just-- it was just like it was a dream that just woken up from it, it wasn't really real.

Angie: Krista, it's a very rare form of cancer that you were diagnosed with. Where did you turn to or who did you turn to for support?

Krista: That was a really good question. Actually, I didn't have much support because we were obviously in the middle of lockdown. The doctors were as supportive as they possibly could be, but we were in the middle of a global pandemic, so I probably didn't get the care that you normally would get. I actually have to say, I have a friend of mine that works from Macmillan. She said, "Have you reached out to Macmillan?" Now, in my mind, I only think of Macmillan nurses. I then literally reached out to Macmillan and I think my stable guidance through the whole thing, the stable support that I had through the whole of this journey was Macmillan. It came with so many different areas to help support me. It came from my mental well-being, food, to my physical appearance and what I was about to experience with my hair loss, and with support about fertility and what to do in that regards. Financial support as well. I was gifted a grant from Macmillan which really, really helped. I was also gifted the opportunity to speak to a financial advisor. I had savings in the bank, but it was something that I hadn't prepared for, and then learning what the treatment was and the process that I had to go through in order to get myself back to good health was not just a quick fix, and so you have concerns about, what am I going to do? How am I going to support myself financially? Among a whole array of different questions that came up, every single one of them could be supported and answered by Macmillan. They also gave me a safe place to talk about what was wrong and how I was going to get through what I needed to get through. Everybody that I met face-to-face and over the phone was just a delight. They very much were positive and bright and cheerful and optimistic, and really held my hand through the whole process, I have to be honest. Whereas things like dealing with telling your friends and your family, they were there the whole way through to help me with that process. Angie: I know that losing your hair, that was quite a huge thing for you, wasn't it, because you had very, very long hair, didn't you?

Krista: Yes. It sounds very arrogant, but losing my hair was huge, absolutely huge. I think as a woman, you're losing your identity. For me, I was able to keep the fact that I was unwell under wraps for quite a long time even when I was doing home chemo. I had someone who came up to me and said, "Wow, you're the healthiest looking sick person I've ever met," but when the hair goes, that's when people know. That's when people start to see things. We did a little bit of a ritual with some friends of mine from school and we got together and I took it into my own hands to actually take my hair off. I laugh and joke now and I say 2020 was the year of the hairstyles, because I literally went from long hair to medium hair to then short hair, to then doing a buzz cut, which was very, very different for me for sure.

Angie: Having spoken about the diagnosis, and I'm really pleased to hear that it was Macmillan, and of course your friends, et cetera, that got you through this. I know being told you've got cancer's got huge repercussions. People who do suffer from this awful disease, they tend to go to a hospital. They have that treatment together. You had it by yourself at home. That's a lot of time to think, isn't it?

Krista: Yes, it is. It is a long time to think. For me, it's like the pandemic didn't happen because I had so many other things to concentrate on. The only issue that I had with it was because a global pandemic is a new thing. For me, being able to go outside when you're feeling a bit rough and you're not feeling that great to go and sit in a coffee shop and have a nice coffee and just get yourself out of the house or go for a nice walk or go and meet someone to take your mind off it is obviously what you would go to, but because of the restrictions and what was happening, I was just stuck in at home. I would literally spend a lot of time finding people that had gone through adversity and had come out the other end. I would just look for inspiration on the internet. That became my way of escaping what was actually happening and going on because it was a tough time. It was a rough ride as well and I had the added process of knowing that my immune system was compromised.

Angie: I know that children was part of your vision for the future. Were you made aware of any of the options available to you, like freezing your eggs?

Krista: Yes, absolutely. Yes. Children was a big thing, but I did actually go to a fertility clinic and we did go through the fertility process. I had the blood tests and I had my ovaries scanned and we did look at freezing my eggs. Unfortunately for me, the disease was progressing very fast. I'd lost the ability to walk and I was losing the ability to use my arms. Even holding a pen or opening a packet of crisps was becoming a really hard task. The disease worked so quickly on my ability from walking to then losing my ability to a walk that it happened literally in the space of four to six weeks. I had a decision to make whether I started home chemo or if I went in and started the fertility process, which I got funding for. The way that the disease was progressing so fast, we decided that actually I needed to start the home chemo straight away rather than going through fertility. In my eyes, I didn't want to come out the other side of this and be disabled and not be able to bring up children. It was a hard pill to swallow,but yes, I decided to go straight into chemotherapy to try and get the disease under control.

Angie: That must have been a very difficult decision to make. I don't want to get too, too dramatic, either your children or your life, but to have to make that decision, knowing that the treatment could possibly make you infertile. That must have been a very, very hard pill to swallow. Can you give me some kind of other issues that were going through your mind at that time?

Krista: Yes, completely. Looking back now, if I can look back now at the situation, I would've done the fertility treatment, but I was scared. I was scared and something was happening to my body that I had no control over at the time and I was getting sicker and sicker and sicker. I was of the mindset that, well, if I don't have a life, I can't have children anyway. Fear drove me to start treatment straight away. Knowing what I know now, moving through the process that it probably would've been okay to have done the fertility treatment, but because there was so much going on and things were getting a lot worse quite quickly, I decided to not do the fertility treatment. I think whether you're young or whether you're old, it's a really hard decision and it's one that I actually have to say, I do regret now coming out the other side of it.

Angie: Okay. Then Krista, what advice would you give to someone else having to make such a decision, cancer treatment or fertility treatment? I know every case is individual and I know not one size fits all, but I'm just asking you, what advice would you give someone that's having to make this decision?

Krista: Absolutely. I would definitely say that really look at the situation and the options. I had words like chemotherapy thrown at me, losing your hair thrown at me, having severe neuropathy in my body thrown at me, and it was terrifying. If I could go over the experience again, I would definitely have gone through the fertility treatment. It was only four weeks out of a program that would've helped me to obviously get some eggs and put them in to freeze, because now after the treatment, I went back and I had my ovaries scanned. I had the blood test scanned and my womb is completely fine to hold and carry and have children, but my eggs got destroyed and I did go straight into perimenopausal and the menopause straight after the treatment. We went back and I was hoping that there would be a little bit of glimmer of hope there, but literally the chemo did destroy everything. I would definitely say to women that are looking at getting into treatment to consider whether you can take that short period of time out and literally put your eggs, freeze them and put them aside because it is a decision that I do regret not taking.

Angie: I'm hearing you, because I think if you've always had it in your heart, in your soul to carry a child, if whatever an experience takes its course then you find that you're not able to do that, it must be quite hard to think about what the next stage would be to become a parent. Does that make sense?

Krista: It makes perfect sense. Absolutely, Angie, it does make sense. There's many children on this planet that need a loving, gorgeous home and that is my second option. I know that it is something that I will get round to at some particular point in time and to be able to foster or adopt a child and give them a beautiful, loving home would be an absolute wonderful experience. I do look at that and just go, yes, that is another option and that is another way to rekindle that purpose of having children, but it's still hard. Back in Australia, I worked with women to help get them pregnant to carry children. I witnessed that whole nine-month process and then the birthing and for me to be able to carry a child, for a woman, I think it really is the expression of femininity and womanhood. It is something that I have let go of for now. I'm always open to miracles and you never know.

Angie: Amen.

Krista: There's like 1% chance and I joke with my friends and I joke with everyone. It's like, my next partner needs to have very strong life force, so I hope he's got that on his daily profile.

Angie: Krista, I love your optimism. I love your optimism. You were approaching 40 and I'm going to assume that you had a picture in your mind of what 40 was going to look like for you. How were you feeling during this time, because I'm pretty sure that this was not what you thought was going to be accompanying your 40th birthday?

Krista: No, it's far off. I envisioned having a big party with friends, beautiful house with a loving partner by my side, just having a really good time. In fact, on my 40th birthday, I literally had a bald head, just come off a stem cell transplant and it was so far from what I was expecting to create for my 40th. I have to wait till my 50th now. Again, I still look at it as just I would never ever saw that one coming. That was a curve ball that just came left of field and it was not what I was expecting at all. I have had to relook at my life, I've had to relook at it and go, wow, how am I going to repurpose all of this? Because I'm turning 41 in December, so it's a year on and I'm like, what does my life look like now? Where am I moving forwards to? How am I going to create my purposes and what do I want to create and how do I want to show up in this world? That is a few questions that I've sat down to ask myself. What is it that I really want to create for myself? Because I feel like I've got a second chance now. As I said, today is quite a significant day. Today is the day last year where I had my stem cell transplant, so it's like where I have a second birthday. On a cellular level, I'm one years old when it comes to my immune system. I've got a little celebration tonight with a birthday cake with a number one candle on it. I'm like the Queen now, I get to have two birthdays.

Angie: Fantastic. Absolutely love your optimism and just your complete positive outlook, because aside from the fertility side of things, do you have any other lasting effects from your treatment?

Krista: Yes, I do. I'm getting better every day and the doctors told me officially in June this year that I am in complete remission and the myeloma which is part of the cancer has completely gone from the blood, but I have neuropathy, so I walk now with leg braces. I still have effects in my arms and my hands. I do struggle with that and the rehabilitation with that. I've got a goal to literally kite surf again and get out there on the water and get my feet working again. I've just recently met an amazing woman who is a world champion rock climber. I've just started rock climbing at my local gym. She actually started rock climbing in a wheelchair and is not just become a world champion once, she's done it three times. In fact, we wear the same braces. Like, oh look, you wear the same braces as me and I'm not actually off the wall yet. They're trying to get my balance sorted and I just hang around like a monkey on the lower levels right now, but I still enjoy it and it's fun and it gives me that glimmer of hope. Surrounding myself with people that are a bit gusto and say, come on, you can do this, has been a magic pill for me.

Angie: I was going to ask you, what are your plans for the future? I'm hearing you want to get out there surfing again, you want to get back to that state of physicality that you had. My assumption is that your number one goal is to have life without those braces or to move as effectively as you possibly can if you have to have those braces.

Krista: Yes 100%. I've already moved through progression. I keep going back to the neurophysios in London and for a while I kept breaking my braces and they were like, will you stop getting better, because we've gotten-- Literally, the braces that they've given me now, there are no other braces that they can give me. I've got to the point where I'm really strong. The doctors said to me, "It would be two to three years before you'd even think about starting to walk and get up again." I've basically obliterated that target and I'm now able to walk on my own without having crutches or anything like that and just use the braces to get around with. There was an element of adapting to a new way of living and I'd still get frustrated a little bit. I still get a little bit down and a little bit sad when I look at what I could do to what I do now, but I just keep focused. I think the other thing for me is, I like to say I was grounded. I literally was grounded and made to stop and really look at things. I started to look at some of the other things that I really loved doing and how I could recreate my business without the physicality that I had before, where I was teaching a lot of people, remedial type work. My business again is taking a different stance, we're going to create more with that. I'm going to partner with more people and I've started to look at what I really enjoy and during that process to keep me sane, I started singing lessons and singing.

Angie: Oh wow.

Krista: I started singing and started to do some acting classes, which at 40 I felt stupid and ridiculous. When I do it, I love it, I enjoy it. I'm just like I'm in that and it's a part of me that maybe I just ignored for a long, long time. This has given me the chance to rehabilitate some of those things that I used to love when I was young and didn't quite follow through on. I now use those types of things as a way to inspire myself, make myself feel good and just little hobbies right now.

Angie: Life after 40 is looking different because of your diagnosis than the life you had thought before diagnosis would look like at 40?

Krista: 100%. It looks completely different to what I had mocked up in my head prior to getting sick. It's taken a new stance and I've had to look at it and think, what am I going to create now? Who is Krista 2.0 and what does she want to do? First and foremost is I really want to throw myself into the philanthropy work and work with children and help support them. Back in Australia I ran school programs for teens. That's a project that I have that I'm looking to rekindle and get that up and running. I think that's really important right now. It's very different to what I first envisaged before I got sick. Probably there's an element of it that it's probably a little bit more exciting than what I had first thought. There's a lot more to achieve. You do get that ability to-- I don't have a family, I don't have a mortgage, so I've got some freedoms that other people may not have. How can I use that to the betterment of really creating a purpose that really helps other people? That's probably at my core, my purpose is to really support other people do well and experience a really good life. How can I use what I have now to create that?

Angie: Krista, are you going to put this experience in a book?

Krista: I've been asked that several times and yes, I have put some musings down on paper and I have a title for it. Maybe it might get published one day.

Angie: Oh, it will get published even if you have to self-publish, but I doubt you will. A publisher is going to grab this story.

Krista: Well, we'll see.

Angie: Krista, thank you so, so much for joining me. Thank you.

Krista: No worries and thank you for having me. It's been a pleasure, absolute pleasure. Thanks Angie.

Moderator: Questions about cancer. Boots and Macmillan are by your side from the moment you're diagnosed through your treatment and beyond. Our Boots Macmillan information pharmacists are on hand with specialist support, from helping you make sense of your diagnosis to advice about living with cancer. You can now access this specialist cancer support at every Boots pharmacy in the UK. Visit boots.com/macmillan for more information. Subject to pharmacist availability.

Angie: Azmina, thank you for joining me today and welcome back. Now, Krista has spoken about her experience with cancer and how treatment affected her fertility. In your experience, talk us through how cancer treatment can impact your fertility?

Azmina: Angie, different types of cancer treatment can affect fertility in different ways. Some of these ways can be only temporary and some of them unfortunately can be permanent, which can basically mean permanent infertility. A lot does depend on not only the type of cancer, but also the type of treatment or treatments, plural, that the doctors are recommending the person should have. It is unfortunate that cancer treatments do have side effects. One of the most devastating things that can happen can be impacts on your fertility, which may not necessarily be obvious at the time that you are choosing to have that treatment.

Angie: Are there types of cancer surgeries that can affect fertility? Is it different for men and women?

Azmina: Absolutely. Cancer surgeries, operations that do involve the pelvic organs, for women and for men can affect fertility, because sometimes when you're having an operation, there can be damage to the nerves which supply those areas. Surgery is definitely one type of cancer treatment that can affect fertility, but also some of the medication treatments like chemotherapy and sometimes even radiotherapy can also affect fertility.

Angie: I was going to ask, for somebody in this position, will there be someone in the healthcare team to talk about the options, the different options?

Azmina: I would hope that today, in the era of what we call holistic and personalized cancer care, which means that doctors and nurses really care about you as a whole person rather than just your cancer, I would very much hope that the healthcare team would talk to the person about this. However, if you don't find that someone's brought it up with you, if the healthcare team don't happen to mention it, then you must absolutely bring it up with them. Ask the questions, open the conversations, and please don't ever feel like you're imposing on a doctor or nurse by asking a question that they haven't already asked you.

Angie: What types of questions should people be asking their medical team when it comes to cancer treatment and fertility, whether male or female?

Azmina: Regardless of the situation that a particular person is facing, you would want to ask the team whether they think that there could be any impacts on your fertility. You would want to know whether those impacts are likely to be temporary and that once your treatment is finished, your fertility would come back. You would also like to ask whether they could be long lasting. You would want to know from the medical team whether there's anything that they can do to avoid the impacts on fertility. That might be talking about a different method of fertility preservation, which means that actually the impacts on your fertility wouldn't be as extreme as they would be otherwise. You would also just want to talk to them about your hopes for the future. Tell the team whether you think your family is complete if you already have children. If you haven't had children yet, tell the team whether or not it's really important to you to be able to have a family in the future.

Angie: Can you tell me a little bit about the different types of fertility preservation?

Azmina: It used to be the case that what we could preserve was actually things like either the eggs or the sperm themselves, but actually, now, as well as just freezing or preserving sperm and eggs themselves, the NHS can actually also preserve the tissues and the organs that create the sperm and eggs. It's now possible to do things like preserve testicular tissue and ovarian tissue. Not in all circumstances, but the possibilities for fertility preservation are changing every day.

Angie: Can a woman get pregnant during cancer treatment?

Azmina: Biologically, it is possible to remain fertile during cancer treatment, but something very important is to actually use contraception during cancer treatment, because-- The healthcare team would explain to you in much more detail about the reasons for this, but essentially, drugs that help to keep cancer under control are called cytotoxic. Cytotoxic means toxic to cells. That means all cells. Cancer cells, which might be bad cells that we want to get rid of, but also good cells. We really, really would very strongly discourage anybody from trying to get pregnant whilst they're having cancer treatment. That goes for men and women.

Angie: Okay. Are there then ways to boost fertility after treatment?

Azmina: In terms of boosting fertility post-treatment, that's something that you really want to discuss with your healthcare team, because there are certain types of cancers that are related to hormones. If you did have one of those types of cancers, you might want to be very careful about boosting your hormones, because what you wouldn't want to do is to accidentally increase your risk of either the cancer coming back or for getting another cancer. Please don't do that without talking to your healthcare team first.

Angie: What kind of support would Macmillan offer?

Azmina: Macmillan has plenty of support out there. If you are worried about your fertility or if you are worried about the future full stop, then please do reach out and talk to us. There's probably a cancer support center inside your local hospital where you're having your cancer treatment. Otherwise, I'd really recommend going to Macmillan's online community, because in the online community, you can actually talk to other people who have similar worries and fears to you yourself. There is lots and lots of help out there. It's just not always that straightforward to find the help. This is where Macmillan can really help out because we're able to connect people, with other sources of specialist support and information that can really, really help them. Please reach out is the message.

Angie: Huge thanks to Krista for her openness and honesty, and thanks to Azmina for sharing such crucial information and guidance. If you're looking for further information about some of the things we've talked about in this episode, or you'd like to donate to Macmillan's vital work, please visit our website, www.macmillan.org.uk/podcast. I'm Angie Greaves. Talking Cancer is a Macmillan cancer support podcast.

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