

Let's talk about: Fertility and cancer

Emma (00:03)

How do you make decisions about your future fertility when you've only just been told you have cancer?

Kreena (00:08)

the day I found out I'd have to have chemotherapy was the day that everything that I thought I could control just came out became out of reach for me.

Emma (00:18)

Hello, I'm Emma and my pronouns are she, her.

Carly (00:21)

And I'm Carly and I go by she/her Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, sharing practical advice, clinical insights and real experiences to help you support people living with cancer.

Emma (00:38)

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Carly (01:01)

This episode contains conversations about fertility and cancer, which you may find upsetting or triggering. Listener discretion is advised.

Carly (01:10)

Hello and welcome to the Cancer Professionals podcast. So today we're talking about the topic of fertility and specifically the impact that cancer and cancer treatment can have on fertility, future family building and life beyond cancer.

Fertility can be a very emotionally significant aspect of a person's cancer experience, but sometimes conversations about fertility maybe don't always happen early enough or cover the full range of options available to someone. So today we're joined by two incredible guests, Kreena and Richard. So welcome to you both. Let's start with some introductions and what brings you to the podcast. Kreena, shall we come to you first?

Kreena (01:52)

Yeah, sure. Hi, everyone. Thank you for having me today. I'm Kreena and I'm a patient ambassador, advocate, storyteller and share my story of navigating breast cancer as a young South Asian woman who came up against quite a lot of stigma during the journey. yeah, I also coincidentally work for Macmillan as head of finance and procurement. So, I'm really, really thankful to be here.

Carly (02:18)

I'm so so pleased that you're able to join us. Thank you. And Richard, over to you.

Richard Anderson (02:23)

Yeah, thanks.

And as Kreena says, great pleasure to be here and discuss this topic. So yeah, I'm Richard Anderson. I'm at the University of Edinburgh. My rather lengthy title is Professor of Clinical Reproductive Science there. And I've been involved in particularly female fertility preservation really with cancer patients for gosh, ridiculously long time actually, it's about 35 years or something now, something like that. And so going back to the early days of ovarian tissue cryopreservation, which is something that we've continued with. And along with that, my other role is I'm a consultant in reproductive medicine in the Royal Infirmary of Edinburgh, seeing patients with fertility and other reproductive endocrine disorders.

Carly (03:04)

Great, thank you, looking forward to learning about that as we go through. So, I think a nice place to start will be, Kreena you mentioned in your introduction about kind of your story and your journey, and I think maybe it might be a good idea to start there. So could you start by telling us a bit about your story and sharing your story and your experience with cancer, but also, obviously, we're here to talk about fertility and where fertility came into that and part of that experience for you.

Kreena (03:34)

Yeah, sure. I'll try and be as brief as I can. I was diagnosed with breast cancer when I was 33 years old. We didn't have any children, and we were certainly wanting, hoping, trying for a family. And so, it was that position that so many young patients find themselves in that they're on, they're in their point of their life where they're looking to the future and then cancer comes along and just, you know, puts a halt to all of those dreams that you're trying to bring to life. And it was a really difficult, difficult time for us. And I think I remember back to those days of my diagnosis. of course, that, hearing the words you have cancer are just brutal and so difficult for a patient to listen to. But then when you dig into it deep in your eye, this isn't just about cancer. This is now about fertility. It's about family. It's about what I thought my future was going to look like and what I'm going to have to give up in the process of getting through this disease. That's when it became really, really difficult for us. So, I went through obviously conversations around fertility, fertility preservation. Hopefully we can talk about that a little bit more and how complicated that is as we get on with the podcast.

In a way fertility overshadowed so much of my treatment plan because it was such a big thing to get through. But it also became the hope that I held on to throughout every round of chemotherapy and every sort of dream living beyond breast cancer. So, it can be quite a double-edged sword, it can be painful, but it can also be, the thing that keeps you going. I'm now, goodness, 13 years outside of my initial diagnosis, which is incredible and where have had really severe health complications along the way so I went through severe heart failure following chemotherapy which is a whole other podcast in itself but that again affected my family building story but I did find a way to have a family and you know my children are here as a result of fertility preservation donor conception surrogacy and you know some of the most

brilliant things that human beings can do for one another and I'm so passionate about leaning into that and finding the good that can come out of these really stormy, stormy situations.

Carly (05:41)

Yeah, absolutely. And what a positive end to that story when you were talking about your children. I'm kind of going back to when you were talking about sort of where that came in and you said that, of course, when you were diagnosed, having a family was something that was really, something that you really wanted. So that was a really big factor of it. How did that kind of affect how you viewed sort of your future within that? I know you talked about that hope side of things, but yeah, how did that affect it?

Kreena (06:09)

It affected, it kind of came in two waves because when I was initially diagnosed, the treatment plan on the table was chest wall radiotherapy only, so mastectomy and then radiotherapy to the chest wall. And because I'd never had fertility issues, we'd never sort of been to an IVF clinic, ordinarily as a couple who were trying to struggling, trying to conceive. I'd never really entered the world of IVF or fertility preservation. So, kind of when I heard that I was having radiotherapy, was like, that's fine.

I'll still be able to have children as normal the radiotherapy is going to be to my chest. It's not going to affect hopefully my ability to have children. And, and so sort of led myself down this path of, okay, this is bad, but it's not as bad as it could be. And then when I went back to see my breast surgeon and they'd sampled my lymph nodes and eventually took out all of my lymph nodes, he was like, so, you know, just to make it clear, you're now going to have to change your treatment plan and chemotherapy will have to be on the table. And that day hit me harder than the day I found out I had breast cancer because the day I found out I'd have to have chemotherapy was the day that everything that I thought I could control just came out became out of reach for me. So I knew that if I had chemo I would lose my hair. I knew there'd be a really good chance of my fertility being compromised. I knew that there'd be other long-term consequences and I'd sort of in the weeks before that sort of conversation with the surgeon my aunt had been saying to me you know what about your fertility I know you want you're trying for children and for an Indian family, that's quite unusual because we don't really talk about trying to have children or struggling to have children. So I'm really thankful to her because she's probably the only person in my entire friend and family circle who said, have you considered what building your family would look like if cancer is going to affect your fertility? And initially I was like, it's not going to because the treatment plan is radiotherapy. And then when chemotherapy came onto the cards, I felt like everything I was clutching onto, I had to let go off because now, now, now that now it was a different ball game. And she had said to me, you need to talk to your oncologist about fertility preservation. I know someone who's been through that and now successfully has children. So was like, okay, there is still an option. But the cancer sort of the priority of my oncologist was to deal with the cancer.

But the priority for my husband and I was to know that if we had a future, it was one that we would be happy with. And children were a part of that. So I went in really early on to one of my appointments and said, look can I preserve my fertility? If I do, what do I need to do? And you know, what's the timeframes? And he was, I mean, the line I always quote, and it's never left me, is that he said his job was to save my life, not to make any more lives. And I still find that really hard. And I love my oncologist. You know, he's a brilliant guy, and you know, he saved my

life. But from the patient's perspective, that is just so hard to hear. And it took a lot of, fortunately I'm quite a blashy person and so I will question it and I'll push it and I'll push it and I was like, so I get that but if I live beyond this disease, I need to know I can live a life that I want to live and that involves children and put it into context, my tumours were 100 % oestrogen and progesterone receptive so we were dealing with hormonally sensitive tumours and so quite rightly so he pointed out, you need to be careful with fertility preservation with oestrogen and sensitive tumours and my husband and I took it away and were like, look, we want to preserve fertility. And so he said, look, I will give you one round because I want you in the chemo chair in two weeks time. So you can go out of here today. And I essentially had 14 days to go through a cycle of egg harvesting, fertility preservation, and putting that in the freezer that whole situation of trying to save your life whilst trying to create another life is just so, so nuanced and complex in terms of one, doing it because, you know, finding the clinic finding the doctor and all of that, but also the mental health implications of that are so difficult. went from one day I'd be really excited that actually I'll have a future, and I might have children in that future to what if I just die before these embryos are brought to life? And my husband and I would always have, we'd have have quite frequent conversations on if the cancer, had its way and if I didn't survive beyond five years or, long enough to bring a baby into this world, what would he do with those embryos? And so I think the cancer and fertility conversation is so complicated because it's not just about preserving fertility and then waiting, it's about planning your future, but in the smallest window of time where you just didn't see it coming. And so it's very hard to navigate it and we came across the obstacles of funding and postcode lotteries and all of those things which are just horrible in itself, when someone's funded and someone else isn't. But then when you overlay cancer on top of it, it's, it's like soul destroying in so many ways. And I guess that's why I share because we've had to go through so many, we've jumped through a lot of hoops to get to where we are today. And I would just like future patients not to have to jump through so many of those hoops.

Carly (11:10)

Yeah, absolutely. And we are so grateful for you, you know, for sharing those stories. and just hearing your firsthand experiences of that. And like you said, the nuances between that you know, thinking about saving your own life and but also thinking about wanting new lives, you know, like the kind of the phrase that you had mentioned, you talked about fertility preservation. really want to come back to that. But I did kind of before that, I just wanted, I was interested to know, Richard, obviously from Kreena we've just heard really the kind of, the importance that that fertility conversation had and throughout that experience for her. But I was interested to know from your perspective, and the people that you've worked with and the work that you've done, Why is it so important to think about and consider that when it comes to people affected by cancer?

Richard Anderson (11:54)

Well, think, yeah, think Kreena has illustrated quite how important it is, isn't it? I mean, you we all very much define ourselves by our families and, you know, it's a truism that family is the most important thing and that's because it's true. You know, we all rely on that more than we define ourselves as a doctor or a podcaster or whatever, don't we? I mean, these are the really fundamental aspects of human life that are so important. actually you said so many things that are worth discussing a bit further during that, Kreena that we can come back to perhaps. But yeah, your recognition and fantastically your aunt picked up and was able to put it in your mind that this is actually something you really needed to do. But it is sad and distressing to hear all

the obstacles that you were certainly not helping you get through that journey, were they, in those early days? Because I think one of the things that we're very aware of is that this is something that needs to be raised right at day one when that diagnosis is first sitting on your oncologist desk and they're thinking about what the treatment's going to involve. And in many patients with cancer, it will involve chemotherapy. And of course, chemotherapy is used much more widely in early breast cancer than it used to be in decades past. So there are a lot more women getting it for early stage disease, obviously then with a very good chance that they will be essentially cured of their condition which is fantastic and that's so much the case across so many diagnoses, although perhaps not sadly not all, but for so many. But you also, I think, mentioned something that's also really important in this perspective is that when we're thinking about fertility and cancer, it isn't just, the treatment going to damage my fertility? It's all the other aspects that have affected yourself as well with the heart complications, for example.

And when we've done surveys of how many women go on to have a baby after cancer, one of the things that is difficult to dissect from that is how much of that is just due to the actually damaging treatment they had to their ovaries or their testicles and males or their reproductive system, and how much is through these other things such as all the other complications you get, such as heart problems that you mentioned there, or changing life expectancies because there may well be also other women who are fortunate enough to have had a child before cancer who's then that diagnosis and that change in their perception of themselves, they think, well, actually, maybe my thoughts about having another baby or another part of my extending my family, maybe that changes just with the whole psychology of the cancer diagnosis as well. So, you know, so there's, it's such a multifaceted part of it, isn't it? It's such a complicated conversation, but you know, as you say, you know, one of the key things you raised is the need to get on with it and have those conversations very urgently at the time. And, you know, there isn't an opportunity to come back in a month's time when you've had time to chew it over. You know, it's now or never for many patients, unfortunately.

Carly (15:13)

Yeah, absolutely. I really took that from what you were sharing, Kreena and like Richard said, you know, the fact that it was great that your auntie was able to start that conversation to then for you to then go and ask all of those questions. And you did, I know I said about fertility preservation, and you did mention Kreena some of the options that were kind of available to you. But I wondered if Richard, you're able to kind of talk a bit more about those fertility preservation options What's available today and also how can professionals help people to understand what are the options and what are some of the choices that they could look into.

Richard Anderson (15:45)

Yeah, so yeah, so it's there's a fairly clear set of pathways to be honest for this, but depending on your whether you're male or female and your age essentially as well. So, for adult women, the most common pathway is egg freezing. And as Kreena has indicated, that's going to take a couple of weeks to go through the ovarian stimulation because it's really essentially the first half of an IVF cycle where you're having daily injections for 12 days or so to stimulate your ovaries and then take the eggs and then being able to freeze them. But of course, you've got to get in contact with the IVF clinic. You've got to have those initial consultations. You can't just walk in and start injections on day one. Although I think there are a lot of things that have been done to really speed things up and referral pathways are now so much better than they were 15, 20 years ago when no one knew who to phone up and there was all sorts of anxieties and so

many oncologists had concerns, just as you've expressed, Kreena that actually, you know, our priority is to cure you and we'll pick up the pieces afterwards rather than thinking of really survivorship from day one, which is now so much part of the oncology mindset, as I understand it as a non-oncologist so there's that referral pathways are often much, much slicker than they used to be. And that needs to be maintained because people come and go and People need to maintain that you've got to those phone numbers and those emails immediately to hand from the oncology team to get in touch with the fertility team.

But there have been technical things as well. So actually, the ability to help women get through egg freezing quickly is actually now better than it was because we've got better pathways of being able to start immediately rather than, know, historically we would wait till your next periods and then you're at the right stage of the cycle. We now really know that that isn't necessary and we've got better ways and better protocols to be able to, you know, just dive in straight away. And so most women would be thinking about freezing eggs. And some women, as you said, Kreena they'll choose to freeze embryos. And that's absolutely appropriate in some instances. But the downside of that is that an embryo that's created like that is the joint property of the man who sperm that. We're used to generate it Which is great if you're in a stable marriage and you want to but if you're a 21-year-old, that isn't going to be an option very often. And there have also been cases where couples have separated. You know, these things happen. And then the man has to be comfortable and give consent for that embryo to be used. And there have been cases where he has declined to do so. And then the woman can't use those embryos because, you know, they're essentially only half hers and they're half his. So, we now are much more freezing eggs even in married women than we might have done historically. And the technology of doing that effectively has also improved dramatically. you when I started in this, we couldn't really freeze eggs. You could freeze embryos, but you couldn't really freeze eggs. And that has completely transformed over the last couple of decades to being a very routine thing these days that, you know, a vitrified egg, which is how we do it, effectively flash frozen in liquid nitrogen, very, very fast freezing. That's essentially almost as good quality when you take it out as it as if it was a fresh egg. the technology has improved dramatically as well. So that would be for, yeah, so

Carly (19:21)

Yeah, what brilliant advancements.

Richard Anderson (19:24)

for adult women and for adult men, course, sperm freezing has been around forever. It's the longest established approach for this. And for younger patients, children, young teenagers, we can freeze a very nautisticular tissue these days. And those are more challenging, more experimental, but they certainly offer opportunities even for the youngest patients these days.

Carly (19:48)

Yeah, that sounds great. Yeah, that sounds interesting. You mentioned, Richard, about the time that it takes for some of those options. If there's a situation where treatment needs to start urgently, how does that change that discussion or the process or the options?

Richard Anderson (20:02)

Yeah, that can be quite a challenge. for many adult women, there is going to be or there can be, I think, sufficient time if everyone is switched on from day one. But the trouble is you can't make

it happen if, previously, you'd often be getting an email from the oncologist on a Friday afternoon saying, I'm starting chemotherapy for this patient on Monday morning. What can you do? And that, think, you know, that is something that has evolved much more positively over the years. But often there will be a balance and there will be a conversation between the oncologist and the patient saying, well, this is what's going to be involved and what are your views here? What are your priorities? And some patients will say, I want the chemotherapy as soon as possible, please. Let's prioritize that. And others will have the sort of views about fertility that Kreena had and say actually this is really so important I want to make sure I have time to do that.

Kreena (20:57)

I think, can I just come in there, Carly? Because I think I only had that view because I didn't know any better or any different. The thing that I always leaned into was I'd been conditioned to believe that having children meant using my own DNA to do so using my own eggs to do so. And so, I was hyper-focused on it, even though the risks of doing so were highlighted to me. And, we said I have children, I have a mixed family. So I have one child who is now eight years old and she was born through, using embryos that were preserved prior to chemotherapy. But I also have three beautiful little boys who are triplets and they're born through donor conception. And what I didn't know at the time of that conversation with my oncologist on let's preserve fertility, because in my head it was the only thing I could do, was that there were other pathways to be had. And I meet so many women who see my story or hear my story or have taken a piece of it away and they're like, I wish I could have preserved my fertility. I didn't have time, I didn't have choice. And I'm like, I just want you to know that there's still other ways to have children because I have children who share my DNA and a child who does three who don't and one that does and the love for them doesn't change, you know, based on the biology that they are. And I really am so passionate about letting people who haven't had the chance to preserve their fertility know that because there are options and yes, our first instinct is, you know, procreation using our own tissues on our own eggs. But if that's not possible, like I kind of feel so passionately about being that story of hope for what else is possible? And I think there are families with adopted children who would say the same thing. Like again, that's another podcast on whether that's the right path for you. so whilst fertility preservation is really, important, it comes with privilege. And I touched on sort of funding being an issue for us. We were denied funding on the NHS initially, despite being in a postcode that was funded and the answer was, we're not going to do it because you haven't been trying to conceive for long enough. I had to really, again, I really push and take nice guidelines to my CCG at the time, my GP at the time, and be like that you need to fund this. all those arguments, you know, all those discussions and emails and arguments took up energy, but they took up precious time, right? I had 14 days. Luckily we were in a, you know, we do have privilege and we were able to put the cost on our credit cards. And, you know, it was an unplanned expense, but yeah, we could absorb it. And for some people, they can't do that. And if you can't do that, and that door therefore closes, like, you know, there are other ways to do this, or, there are support groups available for being child free, not by choice. And I think it's really important we acknowledge those cohorts of people. Because this conversation can be quite triggering to some people who haven't had the option to preserve fertility or who don't have the money to pay for it upfront, whilst you know, the NHS figures its admin out on who's going to pay for it or whose families just don't want them to go through IVF because of the cultural stigma or shame that comes with it. So there's just so many nuances within the fertility conversation that we have to be so careful about when we're talking about preservation and the future it brings. whilst it's amazing that we can preserve fertility, so many other people's stories as well.

Richard Anderson (24:14)

No, I think it's such an important message to get across is that, as you say, Kreena egg donation, sperm donation, these are available treatments and often extremely successful there's certainly options and it's important that you mentioned adoption as well as another option and that can be, you know, such a pathway to happiness for couples where other avenues weren't possible.

Emma (24:36)

you've both shared that so powerfully in your messages there that there are so many routes to parenthood and actually it is very nuanced and it's so individualised and so personalised as to what is the right route for that person, for that family. And it's not just those practical steps of sending off the emails, finding the doctor, but there's also all those emotions that go with it as well. It is such a complex time. And I wondered when we're talking about some of those conversations that health professionals are having. Richard, from kind of your perspective and from kind of the work you've been doing, what are some of the assumptions that you're aware of around fertility preservation, donor conception, surrogacy, and other family building options, and how that shapes conversations between professionals and a person whose fertility is affected by cancer and treatments?

Richard Anderson (25:29)

I think one of the things that you raised there, that is such an important part of the way we try and run the service within the health services limitations, of course, we don't have an endless opportunity to these, is really trying to assess what is the risk to this person of the treatment they can have, because many, many people will go through cancer and remain fertile afterwards. This is absolutely not a universal experience that you lose fertility particularly for children and teenagers, the great majority of those patients will go on to be fertile adults. So, you you're trying to identify the, in the children's context, it's like the one in 10 cancer patients who are going to really need something, whereas the other eight or nine are actually going to be probably fine. And therefore intervening, and especially in a child where you're going to be doing an operation and perhaps removing a bit of a testicle or a bit of an ovary, you've got to be very sure that actually, you know, really this is the right patient and you're doing the right thing and there isn't the opportunity to do harm even sometimes by over-medicalising or over-highlighting the risk. So that's an important aspect for many people to try and identify that. And that's a challenge because of course, to really know what that risk is, you've got to be able to have studied those treatments for actually probably quite a long time to see what happens to people, whether they really are fertile and go on and have the family they want afterwards. so doing that sort of scientific endeavour when oncologists are forever inventing new treatments and moving the goalposts effectively, trying to keep up with this sort of shifting landscape is challenging for everybody concerned. And we do a lot of things in this field essentially based on very incomplete knowledge of it and just using our best knowledge of what we think is right from what's been done before and trying to make intelligent interpretations of this. So that can often be the difficulty. And I think you also, the other aspect that you alluded to, Kreena which I think is such an important difference between the sort of infertility type world of medicine and oncology is that unfortunately across the board in the UK, fertility is essentially a rationed treatment and so as a fertility doctor, you spend a lot of time saying to someone, I'm afraid the NHS will not provide the treatment that you need. And that may be because of your age, it may be because of your weight, it may be because you've already got a child. These are common

reasons. getting, think one of the things I spend quite a lot of time is sort of discussing that with oncologists, because of course that isn't how they work.

Emma (28:20)

And I can imagine those are quite complex conversations about exploring those options and that real importance of those timely conversations. So people can take that information away and think, what is the right route for me? And it isn't always going to be the same route as everybody else. I think that alludes back to Kreena what you had said before about the conversations you've had with so many people who have maybe not had all of the same options or didn't know what all of their options were. And I wondered, Kreena from the work you do and from people that you speak with, have you heard of kind of assumptions that have been made about whether particular fertility preservation or conception, surrogacy, are those barriers that people are facing that you're hearing about?

Kreena (29:03)

Yeah, they are. what's really complicated in the oncology and fertility space is it's the time because it is so time pressured and you're trying to unpack really complicated conversations that you wouldn't normally ask someone to make a decision on how, what type of parent they want to be in the space of 14 days. if someone's going to be considering adoption or donor conception, surrogacy, that's years of work before you actually make that decision and that's not available to people who are, you know, facing chemotherapy in 14 days. thinking of what professionals can do it's how can we help professionals give the stories of hope that patients need to see, the correct factual evidence and information that they need to have at their fingertips, know, all of the options. Because again, like, you know, when it was my time, and I know it's the same for so many other people going through this issue, it's very rare that an oncologist will say, if you can't preserve your fertility or it doesn't sit right to you, donor conception might be an option. That's just sort of not even in their world or, you if you for whatever reason, breast cancer, and you're an endocrine therapy for 10 years, so there's a risk of breaking that at any point to get pregnant if there is one. And surrogacy could be an option for you. we have an organisation called the Intended Parent and it supports people going through surrogacy. We have so many people come to our doors saying, I thought it was illegal, or I thought I had to go overseas or, you know, just misconceptions because UK law is so complex when it comes to surrogacy. I guess the fortune that I had was that we preserved fertility thinking I would carry the child. My heart failure then happened, which meant we had to take an alternate path. But that gave me years almost to explore surrogacy and think what does this mean? What is the law? Where are the resources I need? If someone's trying to make that decision in the space of a couple of days before chemo, it'd be great if their medical teams or their you know specialist nurse has that access, has the information available for them to know where to go. And so I think a real barrier is information. I think also sort of just not seeing those stories of hope can be a real barrier because the amount of people who have come to me previously and be like, I can't do that, I can't do that. you know, I'll be like, of course you can, because let's start small and let's think about what's important to you. you know, gently, gently coach people through what it might be to become a donor conceived pair they get there in the end, but they just needed the time. Like one of the most rewarding things in life after cancer for me is the woman who turns up in my inbox and says, I have a baby because I've seen you share your story and I would never have gone there before. But watching you with your children made me realise I can love a child who's not genetically mine in the same way. And I think that is so powerful. know, clinicians can give us all of the information in the world, but until we see

someone living and breathing that reality that might one day be ours. It's really hard to imagine it. So I think that yes, there are barriers and I'm not saying any of this is easy. It is really hard stuff and it takes, a lot of resolve and grit to get through it. puts pressure on relationships. pushes you to your limits. But in a way, if you do get there, like I always say to my husband, like I don't think anything's going to break us now, you know, as much as he winds me up for not emptying the dishwasher or whatever else it is that he doesn't do, you know, the fact that you've managed to get through such difficult, complex conversations and you've managed to give up, I think for a woman and definitely for me, there was so much grief around our second pregnancy, which was the donor conception and surrogacy. think surrogacy in itself as a fertile woman, pre-cancer, it's really triggering to go through it because you're having to surrender everything you thought was natural and you question your femininity, you question your worth. When my daughter was born, like I was quite extreme. I didn't let anyone feed her because I was like, I need her to know I'm her mum. And if I haven't birthed her, she hasn't heard my voice. How does she know it's me and not my sister who's in my house all the time, let's say. So it can really push you and donor conception again pushed us even further. And, you know, I remember rowing with my husband once and I'm like, they're biologically yours. You don't understand. And I think it, like I just want particularly females to know that it's all right to feel all of that grief and sadness and sorrow because you've had to let go a massive part of the person you thought you were going to be. I'm like, back to the top of the conversation, Richard said like a massive part of your identity is having to take another shape. And so it's going to be difficult. Like there's not much in this conversation that's actually easy. It's all really difficult and that's your biggest barrier. And how can we support people getting through all of those really nuanced complex conversations that they need to make it through. What's the saying? You can't go over or under your struggles, you've just got to work your way through them. So how can we help people through? I think that has to be such a priority for us.

Richard Anderson (33:52)

Yeah, and there's such a lot of information to be shared at a time when, clearly as a new diagnosis, you're reeling with that and with all the tests that have been done. And of course, your oncology team are devising the right therapy for you. you know, these are things that are never terribly straightforward. So, yes, sharing information. I mean, I can't see a world realistically where oncologists are going to be up to speed with the latest nuances and surrogacy because that's terribly complicated even for a fertility team, to be honest.

A lot of IVF clinics don't want to have anything to do with surrogacy, is a challenge in itself. But signposting to the relevant places where patients can find the right information, as well as the consultations that you'd hope that they would be having, but this is a real need. And of course then there's the need to keep them up to date, keep refreshing them. These are all really challenging aspects of trying to do this.

Emma (34:47)

Yeah. And from navigating that uncertainty, that change in your plans, having to have that resilience to keep looking for that information and persevere and have that hope to support you through. And I think that message of hope that you shared, Kreena is so valuable and so important. And I wanted to pick up on that a little bit.

In terms of what would you want professionals to know when they're supporting someone through that time when they're struggling to find or to have hope while they're navigating that

impact on their fertility? Is there anything that you would say to those professionals or that you would kind of signpost them to so that they can support somebody through that period of uncertainty and those hardships?

Kreena (35:32)

I think it's a bit like what Richard just said, we don't expect them to be the experts in that space because it's ever changing, but what we do need is them to signpost people to the right places and to do so in a way that's, I guess, culturally competent as well, to understand that actually fertility is different for different people from different communities for different reasons. again, you know, for us, there was I have never met, I had never met at that point an Indian girl who'd been through surrogacy. And so, whilst you could signpost me to surrogacy forums and agencies, everyone in them was white. And one of the biggest fears I had when I first entered that world was like, will a white woman want to carry a brown baby? You know, and I remember actually posting that in a forum. I'm like, I just don't know, I don't see anyone in here who's a person of colour. And what does that mean for me as an intended mother, who's a person of colour, so I think it's understanding that, yes, we can signpost people, but are they what sort of caveat do we put on that signposting? you might not be this is what I know about surrogacy, but it might not be representative of you exactly. But it's an avenue to start exploring to see if it works for you. And similarly, when it came to donor conception, I think if anyone listens to this and are from marginalised communities, the wait times for donor for donor eggs are so long if you're from black or Asian, black or South Asian or any Asian community actually, just signposting to an egg bank might not be very helpful because they're not going to have a match actually, again, saying like, if I introduce you to this egg bank, I don't know if that's going to be the right path for you, but it might be the first step and you might get the next bit of information or, or move on from there. We ended up having to get our donor was from South Africa because they had Indian donors there and I couldn't get access to an Indian donor here. And we also wanted known egg donor because I wanted to know the woman who was helping me build my family and that brought in another layer of complication on what's allowed in the UK and what's not allowed in the UK. it's signposting, knowing that you don't have all of the answers, but knowing that also the place you're signposting to might not be perfect for that patient, but it opens the door for them to explore a bit more. And beyond that, think social media can be brilliant for connecting communities and finding the stories of hope or the stories that are more similar to yours. So yeah, access to those signposts with a bit of a caveat.

Emma (38:04)

Yeah. And I think you've really raised that important point that actually fertility conversations do need to be inclusive. They need to be culturally responsive. And I think that acknowledgement of having those initial conversations, like Richard said earlier, setting those expectations, sharing that this may not be the right step, but it's a starting point to begin those conversations. And I wondered, Richard, from your perspective as well,

you got any additional thoughts on how fertility conversations can be more inclusive and more responsive?

Richard Anderson (38:37)

It's certainly very difficult to raise these sorts of issues, because the community that you live and work in is going to be limited often by the people coming forward as egg donors.

Certainly, working in Scotland, we are a less diverse culture than there are in parts of England. And so, essentially to find non-Caucasian donors is extraordinarily challenging. So, yeah, this is really a barrier for many people and they often patients will end up going abroad. And therefore, that's going to be financially preclusive for many of them. It just can't happen. So, these are real challenges that we're up against to broaden these opportunities.

Emma (39:16)

It sounds like there's a real balance that needs to exist between supporting hope and supporting someone to maintain that hope through treatment and after treatment and that maintaining realistic expectations of what is available and how easily that can be accessed.

Richard Anderson (39:33)

But I think, sorry, just to pick up on that, Emma, I think it goes back to actually what Kreena said right at the beginning of actually this is, it's a discussion that implies an existence in the future, having that conversation at day one, which is actually often terribly important. And speaking to colleagues, particularly in paediatric oncology, to have that conversation with the child and the parents, you are foreseeing a time in 20 years when they will become parents. essentially, it's not a terribly subliminal message, but it's a very important message that actually the only reason we're having this conversation, because that's what we're working towards, that's what we're expecting.

Carly (40:11)

Mm-hmm. Yeah, so important.

Kreena (40:13)

I think coming back Emma to what you are saying about hope because I know in community hope can be such a it can be a really triggering thing to say, you said, a hold on to hope. it can also be a really brilliant thing because people hold on to hope. we all know that network and community can be so powerful when you're diagnosed. And one of the most powerful things I've heard is people in community saying, find someone who can hold the hope for you when you don't have hope some of the people in community who've helped me, I mean, I've not known them before cancer, and they've come into my life, yet people you've known for 20 years, precancer disappear from your life. And it's like, who can I find to be my person who will stand by me and tell me when actually, I think that door is closed and you'll keep backing against a closed door, you need someone who's going to sit down with you and look at what's the next option, what's the next, thing we could explore and just hold you because like we've said, you've got so much going on where you're brand newly diagnosed with cancer, life has changed in every way, shape and form and now you're like being asked to reimagine a future, but you don't know if that future even exists, like it's really lonely to do that on your own.

Carly (41:21)

Yeah, absolutely. I think That's lovely advice and kind of picking up on what we've been talking about the importance of conversations. Obviously, we've talked about the importance of having conversations early on. We talked a bit about signposting, culturally appropriate signposting that is kind of right for them. One thing I was interested to know is and this is a question to either

of you, what advice would you give to professionals who maybe feel uncertain about having these conversations? Because like you said, there are some people, these conversations are something, they would never have thought about it. And I guess you're in some situations propelling them into thinking about that future that they might not have ever thought about. If a professional feels uncertain about that or a bit worried about how to bring that up what advice would you give to them?

Richard Anderson (42:10)

Should I kick off? Yeah, I think it is difficult. We all have areas that we feel uncertain about how to address something with a patient when it's not your particular area. But I think often the way is just to try it and you'll often do a lot better than you think you're going to because the fact that you recognise this as being a problem is itself probably an indicator that you're probably a bit more, a bit better at it, a bit more knowledgeable about it than you thought you were. And that's why you're questioning yourself. And if you really didn't know anything, you wouldn't know enough to question yourself probably. But I think one of the things that we've really seen over recent years is there is so much more recognition of the importance of this enthusiasm to bring this into care amongst oncologists because it used to be the case that referral was a rare thing and now it's so much more common and so much more urgent than it used to be. And I think this is something that within the NHS that we can actually do well. Specifically talking to American colleagues where geography and money are such limiting factors for the care they can provide to their patients. Actually, in the UK I think we can do a good job here. Obviously not the best sometimes, I think this is an area where the way medicine works in the UK can actually be to our patients' advantage.

Carly (43:32)

Yeah, absolutely. Kreena is there anything maybe from your experiences of conversations you'd have to add into that?

Kreena (43:38)

Yeah, I would just say, for the professionals who listen to this you just never know the power of your words and actually the impact you'll have on someone's life. like you said, like Richard says, like, I'd so much rather you brought it up and I ask you or I tell you that it's not of interest to me than no one ever bring it up because then you miss the boat and we don't have much time when it comes to fertility preservation. So, yes, bring it up, bring it up cautiously. But I think it's really important that even though it feels uncomfortable, you find the courage to have that conversation with your patients because it could change the trajectory of their lives. it's so, so important.

Emma (44:13)

Yeah, and it sounds as though there's a role and a responsibility that all professionals can take in this whether it's working in the chemotherapy unit and it's asking somebody have you got any questions other things that you.

that I can help you with or have you been signposted, whether it's somebody who is a doctor working in primary care, there's a role that everybody can take in having those supportive conversations.

And that actually brings us towards our final question believe it or not. So, the question I'd like to ask you both is what would you like listeners to take away from this episode and Kreena if I could come to you first please.

Kreena (44:50)

Sure, think it depends who the listener is, but for professionals, I hope you take away that there's more than one path to parenthood and to make sure your patients know that all of the options are available, that are available to them. And then for the person like me who's going through this, I just want them to know that that it can be okay, and there can be a future the one that you'd never imagined coming.

Emma (45:11)

Richard, coming to you, what would you like listeners to take away from this episode?

Richard Anderson (45:17)

I think the most important thing is an awareness of where there is a risk. This is an opportunity to do something about it. But time is always going to be short and maintaining that awareness and then the ability to do something about it with links to your fertility unit. And also there's the signposts in that we're discussing so patients can have a think of what's right for them because this isn't necessary or appropriate for everyone. There's quite a lot of nuance to it So just having more knowledge in the appropriate oncology community about how best to approach this and having those interactions with your fertility colleagues to work out what you can really do for your patients.

Kreena (45:57)

for the patient who's listening to this, It does get better from that day when you've been told I have cancer. And one of the quotes that I kind of live my life by and when I look back at, you know, the version of me who was newly diagnosed, I kind of say to her that maybe the storm isn't taking you away from something you thought you needed. Maybe it's taking you towards something better than you could ever have imagined. And sort of lean into that, you know, yes, there's uncertainty, but uncertainty brings with it possibility.

Carly (46:23)

lovely. That's such a great quote.

Emma (46:23)

a really powerful quote

Carly (46:25)

Yeah. Thank you so much for sharing. And yeah, just to kind of close, just to say thank you so much to you both, Richard and Kreena for being part of this conversation. I feel like we've covered so much in such a short period of time, and I've definitely taken so much from it and learnt a lot. I think for me, you know, what has really struck me is actually the importance of

healthcare professionals and the role that they have to play in things like starting those fertility conversations early, having that kind of appropriate signposting and making sure and helping

people to understand those options and the choices that they have. And like you said, Kreena that there's lots of options there. So really helping healthcare professionals to understand that and being able to share those with people they're supporting. And then of course, helping people build that hope as well and how we can do that and the role that we have to play in that. just to say thank you both so much for your time to join us on the Cancer Professionals podcast.

Kreena (47:26)

Thank you for having me.

Richard Anderson (47:26)

Great pleasure to discuss this. Thank you.

Emma (47:29)

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Carly (47:55)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Elvin Box, Men's Health Advocate who will be sharing his lived experience, Dr. Joe Ashcroft, Consultant Clinical Psychologist and Lead for the Macmillan Cancer Psychological Support Service, and Caitlin Harvey, Macmillan's Head of Nursing for Cancer to talk about how cancer and its treatments can affect sex and intimacy.

Emma (48:20)

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Carly (48:34)

I'm Carly.

Emma (48:36)

And I'm Emma, and you have been listening to the Cancer Professional Podcast by Macmillan Cancer Support.