Transcript: Let’s talk about: Pregnancy and cancer

Paul (00:05)

What happens when the excitement and anticipation of pregnancy collides with the shock of a cancer diagnosis?

Ellie (00:12)

it was like just completely devastating. Cause you spend twenty-six weeks planning your life is changing so positively and something that you never imagine is gonna happen to you ever happens at that stage.

Paul (00:24)

Hello, I'm Paul and my pronouns are he him.

Emma (00:27)

And I'm Emma 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.

Paul (00:45)

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Emma (01:09)

This episode includes conversations about pregnancy, cancer, and the possibility of pregnancy and baby loss. We recognise that these topics may be difficult or upsetting for some listeners, so please take care while listening.

Paul (01:23)

So, pregnancy can bring a huge amount of change and uncertainty. Add a cancer diagnosis into that experience, and suddenly someone can find themselves navigating two very different worlds of healthcare at the same time. Around one in a thousand pregnancies are affected by cancer, with cancers such as breast cancer and lymphoma among those that can be diagnosed.

In this episode, though, we want to focus particularly on the person behind the statistics. What is it actually like to experience cancer during pregnancy? What might healthcare professionals not always see or think to ask about? And what can we do differently to provide better, more joined-up support? To explore this with us, we're joined by Ellie Flanagan, who was diagnosed with lymphoma during pregnancy.

And Kate Stockton, the clinical nurse specialist who supported Ellie through her treatment and beyond. Ellie and Kate, welcome to the Cancer Professionals Podcast. It's lovely to have you both with us. And Ellie, perhaps we could start with you. Could you introduce yourself and tell us a little bit about what brings you to the podcast today?

Ellie (02:29)

Yeah, so I'm Ellie, I'm a GP and at twenty-six weeks pregnant, I was diagnosed with a rare and aggressive form of lymphoma. everything happened quite quickly. so within a couple of weeks of diagnosis, I started chemotherapy while pregnant. That continued for the rest of my pregnancy and also postpartum. and so far, I've tried to use my experience to kind of raise awareness as much as possible, really.

Paul (02:55)

Lovely, thank you. And Kate?

Kate (02:58)

my name is Kate. So my background is in haematology and oncology where I've worked as a nurse for the last 15 years. I recently started my ACP (Advanced Clinical Practitioner) training but my role previous to this was as a Hematology Specialist Nurse and that's where I met Ellie and it's where a lot of my experience of looking after women who are going through cancer and pregnancy at the same time comes from.

Paul (03:23)

Lovely, thank you, Kate. So Ellie, perhaps the best place to start is with you if that's okay. Before all of this happened, cancer during pregnancy probably wasn't something that you ever expected to encounter. And could you maybe take us back to when you first realised something wasn't quite right and what happened from there?

Ellie (03:43)

Yeah, so it actually happened really quickly. So I'd been it's really hard to know what was pregnancy and what was this in the background, but the actual symptoms started really quickly. So, I'd actually been for a walk, seven mile walk in the peaks in the morning, up and down the hills, slightly breathless, but no more than I'd think it's twenty-six weeks pregnant. And then by that evening I was lying on the sofa at home, and I couldn't take a deep breath in and I knew something was wrong but I didn't ever expect what it turned out to be. I thought it might be a PE (Pulmonary embolism) because I was pregnant. so we went up to A E and I had an X-ray to start with, which showed something, but they weren't really sure. Went on to have a CT. And I thought it was bit strange because no one came to tell me the results for a really like a really long time. And I was on the medical ward pro I'd been in Hospital for over 24 hours, and the consultant came at about 7 pm on a Saturday, came on introduced herself, said, you're a GP, aren't you? What do you know so far? And just that opening, I knew that the next thing wasn't going to be good. so she actually sat on the bed next to me, and I think she held my hand like quite quickly.

And she said you've got an 11 centimetre anterior mediastinal mass. And from then I don't remember much of the conversation. she thought it was a thymoma at first, that's the most common thing to get in that area. It's rare as well, but she thought that's that that's what it was. And from that moment on, it was like just completely devastating. Cause you spend twenty-six weeks planning your life is changing so positively and something that you never imagine is gonna happen to you ever happens at that stage.

And yeah, I hope I never experienced anything like that again, but because of where it is and what was around it, it's right up to all the major blood vessels. And looking at the scan, I think sometimes I wish I didn't know I don't know enough I knew a little bit to know that it was bad and that night, those few days before, like waiting for biopsy, waiting for results, I spent a period of time thinking that it would be inoperable, incurable, and facing that, I faced that for about 10 days. Luckily, the biopsy happened quite quickly and was called and the biopsy was processed really quickly and I got the results really quickly. And the consultant called me to say that it was a lymphoma and said, look, this is we think it's what's called a primary mediastinal B cell lymphoma. I'd never heard of this before. but it's very, very treatable and often curable after one round of treatment. And it sounds very strange. I never thought I'd be relieved to be diagnosed with lymphoma but because we'd spent ten days worst case scenario, the diagnosis came as a bit of a relief and partly because there was a plan and there was some certainty. so, we went out for like brunch to not celebrate, but just to have some news that was it felt positive because I remember going to see the cardiothoracic surgeon between then and the diagnosis and my husband saying, Will she be okay? And he said, we'll look after her. And that was it he couldn't say yes. so it was a it was a whirlwind and the diagnosis was actually like a relief in a very strange way, if that makes sense. So that's the story, of how I got diagnosed.

Paul (07:17)

Thank you. No, really appreciate sharing that with us. can I ask what were some of the thoughts and emotions that were going through your mind while all of this was happening?

Ellie (07:28)

I think I was based with my own mortality just to be on like I thought that I might not survive and being pregnant and being faced with that is awful because it's an awful thing to say, but I had like feelings about I don't want to be pregnant, but not because I didn't want a baby, just because I couldn't cope with the fact that I might not live To see them grow up, or the pregnancy might not progress because I've got cancer and that's my fault. So there's a real mix of emotions that you're dealing with on top of that. and also then worrying about my husband, are they gonna bring up baby and have to live the rest of his life with that? There was just all these layers because you're pregnant at the same time.

So there was that, and then you're also protecting everyone around you because you can see that that everyone else is devastated. No one really knows what to say. I can remember someone saying to me, it's really at least you're pregnant and at least you're gonna have a baby. And I just was felt like screaming at them, like, no, at least nothing. Like I can't even think about the fact I'm pregnant right now. So those first ten days, I can just remember because we didn't decide we didn't want to know the gender of the baby before the she was born. but I was like, we need something positive. So we ended up finding out we're having a little girl, partly because I just had lost any connection to being pregnant in those few days. So that really helped us because then I was like, it's a little girl, I can focus on that. But we had like a little gender reveal, which I'd never I'd never have done something like that before.

But I can remember having all of our family there and sitting there and thinking like it felt like, am I saying goodbye. It was awful. So those ten days were just yeah, and nothing since then has felt anything like that. it's been difficult. But yeah, it's nothing compares to that period of waiting, really.

Paul (09:24)

That's so hard to deal with when, we're with everything going on all at the same time.

Ellie (09:28)

Yeah.

Paul (09:29)

And I wonder kind of what kind of support were you getting from other services at this time?

Ellie (09:37)

In that period I'd not really got an anything because you're in you kind of don't have a team yet because they no one knows what it is. So if that makes sense. So I'd seen a cardiothoracic surgeon because we thought it was a thymoma. and they were like as good as they could be, but no one could tell you anything. I actually contacted Mummy Star, who's a charity for people who have cancer either in pregnancy or immediately after. And it's not their fault, but they wouldn't see me unless I had a diagnosis. they needed a diagnosis or confirmation before they could give me a support worker. I managed to get a letter to them quite quickly, but that period, on my experience was I didn't get loads of support from professionals. But I have my family and friends. I had a lot of support around it, just the professional support in that period. I think it's hard for it to be there though, because you don't know what it is and what you're dealing with.

Paul (10:30)

Yeah, yeah. and looking back now, is there anything that would have helped in that early stage or in that period?

Ellie (10:41)

Yeah, I s I just well just thinking then actually something did help me. When I was went to A and E, I was admitted as an inpatient for a few days after that. And a mental health midwife came and spoke to me the few days on the ward when I was there. And that was really helpful because I could basically just offload all of the dark thoughts I was having so wasn't having to say them to my husband, I now know he was having all the same thoughts as I was, but at the time I don't want him to know that that's what I was thinking. So I did actually get some as an inpatient, but then when I went home I that didn't carry on as much. So I don't know whose remit that would fall under. whether it's a G P checking in or you're contacting a GP, I don't know. But maybe if you're pregnant, the midwife getting in touch. some people might not want to talk to anyone in that time. but I think that really helped me when I was in hospital just to not have to sit with the thoughts myself and just completely off like offload.

Paul (11:41)

Okay, thank you. And Kate, if I could bring you in kind of from the professional perspective, what point did you meet Ellie and what were some of the biggest challenges that were going on at that time?

Kate (11:55)

So I met Ellie after that 10 day period that Ellie talks about there. So I met Ellie on her first face-to-face appointment with the hematology consultant. it's really common during those

appointments that you'll have a consultant and you'll have a nurse specialist. We generally know the results of the biopsy by then. So we know the news that we're going to be breaking and what the patient needs in that appointment in terms of a plan and what kind of support that as a professional you can offer. So I was there to offer support to Ellie and to her family and to give a lot of information about kind of treatment processes and things like that. I mean, those appointments are really difficult anyway. I think even if you don't have cancer and every single patient I've sat in an appointment like that with, they all deal with it different. And so you have to kind of target how much information you can give during those appointments anyway. And sometimes, a patient will hear the word cancer and that's all they'll hear for that appointment. And it doesn't matter, you know, what else is said, that they've heard that word and it's all a blur kind of after that's been said. we like to kind of give written information, things like that. So when they go home, they can read back through and I always spend time after those appointments with the patient, I remember spending time with Ellie and her family after that. those appointments are really complex anyway, without pregnancy in the mix. when you've got a patient that is also pregnant, it adds a lot of additional challenges into kind of the treatment plan and the kind of workup that we would usually do. And, a lot of the challenges depend on how far, someone is in their pregnancy, the type of cancer that we're dealing with, the stage of cancer that we're dealing with, how fast or how slow growing these cancers are how well the patient is. Sometimes, Ellie, was relatively well when we met her. she was, like she said, she'd been walking two weeks before up the Peak District. those kinds of things in this case were in our favor, so to speak, because a lot of what we can do during pregnancy depends very much on where we are kind of in that pregnancy. You know, we wouldn't think about giving treatment in the first trimester but second and third it becomes a lot safer. So there's lots more to work to discuss and work around, with the patient and the family to talk through. Yeah, so it's kind of where we met, isn't it, earlier on your first appointment where we knew what it was and we kind of had a plan

Ellie (14:08)

A plan Yeah, yeah.

Kate (14:10)

of what we were proposing to do. And yet pregnancy, it does add a lot of additional challenges on both sides for the pregnancy and for treating the cancer effectively. I know this won't just be watched by people that are looking after people with the lymphoma and in the stages of pregnancy that Ellie were, is that it all does very much depend on where you are in your pregnancy and all of those other things I've mentioned.

Emma (14:34)

Thank you Kate, I think that really shows doesn't it that actually there are so many considerations when... you're supporting someone with cancer, but actually when somebody is pregnant during cancer, those additional factors such as how far into pregnancy somebody is, their level of fitness, it all plays such an important part in putting together that treatment plan and having those conversations and discussions about next steps and what are those treatment options and what do they look like. And Ellie, I wanted to thank you firstly for sharing how you'd felt during that time and that period of uncertainty and the challenges that that brought you and your family. It sounds like an incredibly difficult time and I just wanted to thank

you for your openness and sharing that with us. And I wondered if I could ask, when you were navigating treatment during pregnancy,

Ellie (15:22)

Yeah.

Emma (15:23)

how did being pregnant influence the decisions that you were faced with?

Ellie (15:28)

one of the things around decisions was about scans and investigations because normally you'd have like a PET CT scan to properly stage it. But I wasn't able to have that because I was pregnant. So I had a full body MRI scan, which is still good, but I imagine I don't know fully, but imagine not quite as effective. and then also when I was in A and E.

I had to make decisions and sign things to say I was happy to have X-rays, I was happy to have CT scans and things, because there's small increased risks of having that obviously radiation during pregnancy. So that was one aspect even before I got the diagnosis. and then like the decisions for me were basically to have treatment, but there wasn't there wasn't another option because if I didn't have treatment, I wouldn't survive the pregnancy. So there was the decisions to have treatment, but it was all discussed and I understood that this was the most effective treatment to have, the risks are small, this is the monitoring we'll do. obviously I decided to have treatment. and then the other complex side of things with the obstetric decisions was particularly around delivery and the date to deliver, because what they don't want to do is you to have chemo and then go into labour two days later or about a week later when your counts are all at their lowest. If you then start going to Labour when you've got no platelets and you've got no immune system, that's not ideal. So my baby was breached, so I was going to end up with a section no matter what. So that's another thing that would be discussed would be like mode of delivery. But that decision was taken away in some regard was actually good because I'd have likely had a section anyway, but it made me feel like the cancer hadn't taken that decision away. Because that's what a lot of these things feel like is like, cancer's taken this, cancer's taken that. so I think there's obviously like the delivery, the actual treatment itself and like the monitoring and scans are heavily affected by having being pregnant while you're going through treatment.

Emma (17:23)

And I think you make a really important point there that that loss of control, the feeling that you can't have control over those decisions. And particularly if that affects your pregnancy decisions as well, that can,

Ellie (17:35)

Yeah.

Emma (17:35)

I imagine, add a huge layer of complexity and quite a lot of distress potentially.

Ellie (17:42)

Yeah, I think I'd have this I obviously everyone has an ideal birth, whatever, but I'd obviously want to have a natural birth and everything. I don't know, in the moment you kind of I found that my mentality was a little bit like, well, you don't have a choice. Like you either go along with this or so I think during the actual treatment and getting to delivery was just like go, go, go, just on to the next thing. And I I seem positive and I was positive 'cause I was gonna have a baby. but then it was actually after she was born that all the things, that was affected 'cause of that. That was affected 'cause of that. All of those thoughts didn't come till after it, really. yeah.

Emma (18:24)

how did you find balancing thinking about your own health alongside your baby's wellbeing?

Ellie (18:32)

the first bit was really, really difficult. once there was a bit of a plan and I knew I did my own reading as well, but I knew that R-CHOP the chemo that I was having, was relatively safe to have during pregnancy and even like long term studies that in terms of it's is very safe. I worried a lot less I worry more about the scans

Paul (18:54)

Mm-hmm.

Ellie (18:54)

it's partly is me overly worrying now she's here. but overall I didn't feel like lots of the worries were taken away from me, if I'm honest, by people making me being included in the decisions, but they weren't my decisions. And I knew they were the best decision at the time. And you just have to go like at the time, that was a decision we made, So I don't have loads of like guilt and worry about the things that could have affected her, partly because I did everything I could to stay as well as I could, and everyone else around me did everything they could to keep me well and keep her well. So I didn't have as much of that as other people might, but it obviously depends on what treatment you're having and what you've had to go through to get the diagnosis as well.

Emma (19:37)

Yeah. And I think Ellie, that description of actually you were included in those conversations, you were part of that decision making, even though some of those decisions were out of your control but being included in those conversations really helped. And Kate, I wondered if I could ask you a question. From your perspective, hearing Ellie talk about being included in those conversations, what does... truly person-centered care look like from your perspective as a specialist nurse for someone who is navigating both pregnancy and cancer?

Kate (20:08)

So I think you need to recognise that any of these things happening to somebody at any one time is incredibly stressful. Being a first time parent, all of the worries that come along with that is incredibly stressful and you have a child and that changes everything about who you are. But also having cancer is incredibly stressful and again changes who you are and I think having those things to navigate individually must be...

so overwhelming but having to navigate those things alongside each other I can't imagine how frightening that must be and I try and be as empathetic as I can with my patients and remembering that they are a person they are somebody that's going through probably the biggest thing they will ever go through simultaneously in their life and so it's really important I think anyway to be open and honest with patients and to kind of say you know when we're discussing treatments, these are the risks, these are the benefits, this is what we want to do. And when you're talking to somebody who's pregnant, it's not just the risks to the patient, it's the risks to their pregnancy as well. And, sometimes those conversations can be really, really difficult because the risks can be catastrophic. And so we have to be open and honest about that, but you need to, I always think to include the patient in that, you know, at the end of the day, this is the patient that it's happening to, this is Ellie that was having, to go through the treatment, these risks are to her health and to her baby's health. And so how can you not include somebody in those kinds of conversations? everything about it affects everything in their life and their world. And, know, our main aim was to balance, Ellie's health and Ellie's pregnancy. We wanted to keep Ellie as well as we possibly could while treating her cancer effectively, but also we wanted to keep her pregnant for as long as possible and get that baby as close to term as possible so that when she was delivered there were less complications on that end as well so you have to you have to include patients in all of these conversations the conversations can be difficult but you just have to you have to be open and honest and like Ellie said, you know, from her perspective, she didn't have a choice because the only alternative was not something that she was prepared to consider. I don't think it's anything any patient in that position would consider. yeah, I think it's just about having open and honest conversations. I remember sitting outside for phlebotomy with Ellie and it's just allowing the patient to have time to process that and talk it through and ask any questions and be there on the end of the phone because they'll go home and think, I should have asked this. And that's where my role as a nurse specialist I loved because you were on the end of the phone and you can phone me the next day and I'll write down all your questions and we'll answer them. So it's just about being available

Ellie (22:45)

just when you're talking about that, it made me remember it so you have to sign a consent form to have the R Chop chemotherapy obviously it's not designed for people who are pregnant and it's all like pre formatted and remember the consultant had to it sounds really frank, but had to write foetal loss like at the end of all the complications and that just like it's it was just like, Yeah, fine that you can do and you just sign that at the time without really you do think about it, but the alternative is well, I won't survive so the baby so there's no there is no choice, but you never ever imagine signing something to say, Yeah, I'll go ahead with that.

Kate (23:23)

It was said, and it is said as bluntly as that.

Ellie (23:26)

Yeah, it was. And I remember the consultant saying that

Kate (23:30)

To give that information is awful, but to receive that information must be 50 million times worse. again, so for me, my role there is to say, have to take these risks, but we're going to do everything we possibly can to stop that from happening, know, have the best possible outcome.

Ellie (23:43)

Yeah. Yeah. Yeah.

'Cause after that conversation, I think you've touched upon it. I it was my mum, dad, my husband, consultant and Kate was in there as well. And then mum, dad and my husband stayed in with the consultant and then I went to get some blood done and Kate came with me and sat next to me. 'Cause she obviously knew that I'd be like spiralling.

And I don't really remember much about the conversation, but I remember her saying to me, I looked after someone else last year in a very similar situation to you. And I met their one-year-old yesterday, and she's still in remission and she's really well. And I like hung on to that through the whole of my treatment. So, I think in the early conversations, giving someone like a little bit of hope when everything feels like rubbish, to put it simply. Like I came away with that obviously loads of other information and I think by that appointment I was at a stage to take in information because I'd had my 'you've got cancer' ten days before and I'd had that not listening to anything after but by the appointment I was like ready to hear what was going to happen. so that was actually for me a positive appointment because I already knew it was bad so I could get all the information I needed and then coming away with a little bit of hope.

Emma (24:56)

And it sounds as though what you're both really eloquently shared is that information sharing at the right point, having those really person-centered conversations, finding out that level of information somebody needs, but also balancing that with the fact that you have to be honest and you have to be very open so that actually you are fully informed and you know what the risks are before proceeding with the treatment. And

Ellie (25:22)

Yeah.

Emma (25:23)

Kate, I wondered from your perspective as a professional who isn't a midwife, isn't an expert in maternity care, for professionals potentially who don't have that specialism of pregnancy or maternity care, what have you learned from supporting Ellie during her pregnancy and her diagnosis and treatment that has kind of really been fundamental for you in how you support somebody who is pregnant with a cancer diagnosis?

Kate (25:48)

lot of things really. learnt a lot of things. As Ellie said, I've looked after other young people before going through pregnancy and the challenges of cancer at the same time. And every journey is so different. I've had patients further along in their pregnancy with less aggressive cancers that we've not had to give chemotherapy to. I've had patients that we know that we've had to start treatment straight away.

For me, it's just about treating every single person as a human being, really. You I am a mom myself and, going through those challenges and going through cancer, having a love one with cancer, this is the most difficult time in somebody's life. And just to be there and to support, to check in, good days and bad days, to be there to talk to when somebody needs that extra space when they don't perhaps want to talk to their family, it's taught me a lot. I know when, towards the kind of end of Ellie's treatment, and we've sat and talked about kind of things that Ellie found really beneficial, having that space just for her and just the importance of not just sitting in on those conversations with the consultants, but just being there available to answer those questions afterwards, to give in the patient space, sometimes away from family, because it's all about, there's a lot going on, isn't there, all at one go? And like Ellie said before, she's having to try and look after other people's emotions, parents and her husband, because Ellie is their world, Ellie is their entire world, and inside Ellie is another part of their world and so Ellie's trying to protect them, but where did Ellie go? who supports? So it's as a professional looking after, my job was to look after Ellie and, whilst we do see patients during pregnancy that develop cancers. It's not common. maybe in the last five years I've looked after five or six women who have been pregnant at the same time as undergoing cancer treatment, so it's not common, but it happens and some people want a lot of information, some people don't. Some people want to know absolutely everything. You just have to get to know your patient, really.

Emma (27:46)

And what advice would you have for professionals? And this is potentially for both of you, but Kate, if I start with you, what advice would you give professionals about working together, for example, across specialities like oncology, maternity services, to provide that seamless support for people facing cancer during pregnancy?

Kate (28:05)

Yeah, this is really important. It's really important. And, you know, particularly at the centre where Ellie was being treated, the maternity services actually were part of another trust. And if anyone that works within the NHS knows that if you're in a different trust, you can't see what the other trust is doing. They can't see our blood results. can't see their, we can't see their notes. They can't see ours. So actually, good collaboration between the two MDTs, so the multidisciplinary teams is vital. And so we, in this case and many other cases before as well, we went really closely with the obstetrics team. the plan for both the pregnancy and the treatment is discussed together and we all have an aim. So in this case, it was to get at least to 37 weeks as close to as possible, knowing we needed to be two weeks after her treatment. But then we couldn't, we didn't want to wait too long then after that because we didn't want to cause delays and, alter the outcome. So working together was really, important. So between every appointment, having open lines of communication, regular MDTs, phone emails, just working as a team is really, really important for that across all kind of obstetrics and, the cancer care side of things. Having the shared aim, but being ready to adapt as well, because we know that pregnancy carries risks and we know that cancer carries risks. And so your risks are doubled there. So the chances of a complication happening with either of those is quite high. So you need to also be kind of prepared for plan B if things do change. thankfully in this case, we worked really well with the obstetrics team. They were brilliant. we had regular MDTs where we would discuss how things were going and Ellie, used to go for, growth scans the day before treatment. And then if everything was okay, would be like, okay, we can press the green button on treatment, but it was knowing that everything lined up with both teams. And also for the patient, it's a lot of appointments. And, as the CNS I would coordinate quite a lot of those

appointments on our side. Ellie would message me, but actually I've got a scan, can I have blood at the same time? And we would just move them because otherwise, the patient will end up coming every single day for appointments. So even practical things, it's really important to work together across all of the teams to make it as seamless as possible, I think.

Emma (30:13)

Ellie, did you have anything you wanted to add to that?

Ellie (30:15)

I think Kate said most of the things. I think the big as a patient, the practical side of putting as much as you can on the same day really helps and things like Kate's already touched upon, they're different trust, which means they can't see each other's bloods. And I had a pick line and the women's hospital wouldn't do bloods, they have different blood bottles. It's like it's really simple, but they have different blood bottles, so they couldn't take the pick line bloods so Kate would walk, despite being different trusts, you could see the building from the women's hospital. Kate would walk across with all the blood stuff and do my bloods for the women's hospital, use my pick line. so it's like making sure that it for me everything was as convenient or as easy as it could be. But as Kate said it was really touch and go as to when she was going to be born and there was one chemo morning where I had a bag packed for section and a bag packed for chemo because I had to go for it. There was a query about growth on the week before. So they'd had like loads of questions and tried to make a plan. And the plan was look, if she's growing and we're happy, you have your chemo and you'll deliver ten days later. So at the time that was just normal part of everyday life and then only like afterwards I thought that's a bit of unusual thing to have to do when you're pregnant but you just get on with it. So everything was really closely monitored. and I don't think I fully appreciated all of that until after. the main thing was planning delivery. And I'm someone who likes to know a plan and have certainty. And there was quite a bit of uncertainty for quite a while with that 'cause we didn't know how I was going to respond to chemo, how the pregnancy was going to progress. But I found it a lot easier to go through treatment once I knew there was a kind of delivery plan and that was ten days after one chemo and then another ten days to restart. So I had a three week break instead of two.

Emma (32:04)

Yeah.

Kate (32:04)

I think patients don't realise also how many people will know of them and about them, that have talked about them, that are involved in their care that actually they never meet because they're part of the bigger picture and the bigger team. And so people would see Ellie's name and know exactly, her case, but perhaps would never meet her because it takes such a huge team to manage all of it.

Ellie (32:25)

Well I would call triage because I had quite a lot of reduced movements and there's no definite link with chemo but it would often happen after chemo and I'd end up going in every time. and before I'd even called they knew who I was. They'd meet me at the door; they'd take me to a side room. I was looked after really, really well. But the amount of people who knew who I was

without me knowing, I remember thinking after I'd got diagnosed, thinking I'm that person that you discuss at the MDT that's the like that's me. I'd be sat in the MDT thinking, it must be awful having cancer and pregnancy and now I'm on the other side. It was a really odd feeling that you're famous is the wrong word, but you're very well known in the women's 'cause they don't get many cancer that it's rare that it happens, like Kate said.

Emma (33:12)

Yeah, and I think it speaks to... you'd mentioned earlier where you it's very unexpected you can't prepare for anything like this happening let alone during pregnancy and the implications that has on your mental well-being your emotional well-being and then also that kind of wanting to protect everybody else around you and we've touched a bit on the importance of being included in conversations and being kept informed of decisions, and I wondered, Ellie, was there anything that looking back and reflecting back on now, are there any kind of conversations that you wish you'd had earlier or information that had been shared at different points potentially?

Ellie (33:54)

I think one thing slightly that I wish I would have talked about a bit more than it and it been addressed a bit more, but I can also understand why it wasn't was like breastfeeding and feeding, because you've got two teams, obviously the you've got the oncology team whose focus is on like treating your cancer, keeping you well, and then the obstetric team is like really closely monitoring your pregnancy, trying to get you safely to delivery and those are the most important things. But at the same time, I am going to be a new mum and it's my first baby. And unfortunately, whether we like it or not, there is this breast is best. And from my experience that's not the case. I didn't I wasn't able to breastfeed and I was told that really early on. And at the time it really didn't feel like a big deal. And it was that I was it was talked about and I said, yeah, that's fine, because I spent a bit of time after like processing the factor couldn't breastfeed and accepted it. But then as it got closer to delivery, that was like on my mind quite a lot. but I did end up bringing it up myself but more with that that's more with the like obstetric side. But I think I know that there's a medication that you can take to suppress lactation, but I already knew that so I was able to ask for that because I knew I would struggle if I had a big milk supply come in. I was feeling a bit unwell having to go back to chemo, not able to breastfeed. I knew I'd find that hard. The medication won't be right for everyone, like, but for me it was safe to have, and I decided that I'd want I wanted that. So, I had that. I now know a bit more that some places you can get donor milk but it's not all hospitals and it's not for everyone. So, I don't even know whether that would have been an option. But at the time I didn't ask for that. It's only like that's in the grand scheme of things, it's a small thing, but I think it would make a difference. And I thought about what could be done. There are infant feeding teams, and it might be that that would you like to discuss feeding with an infant feeding team? At some point, it might be that the person says no because they don't want to think about it, or as soon as they give birth, they do want to. just to say, look, formula feeding is great when you need to. for me, like it meant I had ten days after I had to go to chemo. if I was having to express for like I it would have it meant that other people could look after me, like my daughter, hold her, feed her. I didn't have to worry. I've also had to have a pet scan, a couple of rounds of chemo and even if breastfeeding had been an option, it would have been really, really difficult and she's really healthy, she's gained loads of weight, she feeds really well, she's perfect. when some positive conversations around formula feeding from an infant feeding team probably would have helped me a little bit, but just on that area.

Emma (36:46)

And I'm so pleased to hear that your daughter is doing well and she's growing and it sounds like she's an absolute delight Ellie. So also congratulations. And I think it,

Ellie (36:55)

Thank you. Yeah, it's kind of hard to believe. So

Emma (37:00)

no, you're fine. And I think as well, it really shows the importance of actually revisiting some of those conversations because as you've quite clearly like I said, actually some of how you feel about things change over that pregnancy journey and actually sometimes revisiting those conversations or having those different options can be really useful so thank you for sharing that. And kind of moving on kind of post having your baby what has that period of time been like particularly as your treatments continued and kind of life has moved on as you've gone through treatment.

Ellie (37:36)

Yeah. it's like it's hard. There's probably like two aspects to it. There's one, obviously there's this immense like joy, the best thing that's ever happened to me, having Maeve, and she brought so much joy in what was such an awful, awful time in my life. so you've got this like bundle of joy and happiness that you've like looking after. but then on the other hand, she's born and it's like, I've still got cancer, you know? Like you've had two focuses. You've got this positive focus of getting to delivery and then that goes. So obviously May's a positive focus, but the hospital appointments stop and you've just got chemo and I had a bit more time to think because as Kate said, I was at the hospital all of the time. There was one day when I went five days without being at the hospital and I was like, nearly make a I'll nearly make a week, but I didn't but so you're just there all the time and then that just stops. And I had a little bit more space to start to really think about what happened and thinking back to the really early days of how I thought and like felt. I'd not thought about that again because I probably just didn't have the mental space. So it was a really like amazing time, but also really difficult. Like ten days later I was back at chemo, like leaving a ten day old baby to have chemotherapy is hard. And then I felt quite wiped out the day after and then I had to do it again two weeks later. And we've I've spoken to my husband about this and joked about it. But having Maeve is like the least stressful part of my life. Like I never thought I would say that but having a newborn has been bliss. because I've 'cause I've got cancer and that's just awful she's bought so much joy and a distraction, a positive focus. So it I'd never say having it while you're pregnant, it's it I'm trying to look at the positive side of getting cancer when you're pregnant, is that at least you have something for me, I had something positive. and that I think that's part of how I've tried to cope with it.

Emma (39:38)

And I think that is such a powerful way to think of it. And it speaks, I think, Ellie, to your resilience and the mindset that it sounds like you've approached your treatment and your diagnosis with so looking back from when you were diagnosed, is there anything you wish health care professionals had understood more about those months between your diagnosis and beginning treatment? Not necessarily from maybe Kate's kind of input and support, but thinking more widely about the kind of health care services you might have linked in with or had appointments with.

Ellie (40:14)

if I'm honest, I think my care was actually really good. I think sometimes people ask how you are, but they don't really ask and I think that some Kate always did and I knew that Kate would be asking and then would ask would be like, But like really, like are you know, say it's really hard, isn't it? And I'd be like, Yeah, yeah, it is. But some people Cause outwardly I have been positive and I am positive, but I think people would see that and think that I was okay. But there were some days when I wasn't. so I think sometimes one asking the question but also giving the person the space to answer properly. Because there's one thing ask asking the question and we all do it everyday life. We say, you okay? And someone says, Yeah, and you're like, you're probably not, but I've not got the time But in that scenario, giving someone the space to say, no, actually I'm not today and then ask again and then I don't know. So that would be one thing. My experience was that I had I was quite lucky and that everyone that looked after me did tend to do that, but I think it not always the probably not always the case. I think that's the only real thing that I can think of off the top of my head.

Emma (41:23)

Kate, we'd heard from you earlier kind of talking about giving that space, giving opportunities for Ellie to talk and really kind of having that opportunity for Ellie to express herself independently and away from those kind of concerns for others. And we've heard both you and Ellie share the complexities that pregnancy during cancer brings. And I wondered from your reflections, Kate, from your experiences and your insights as a clinical nurse specialist. When someone is pregnant and gives birth during treatment or after, with those additional emotional and practical challenges, what else could professionals do to provide that additional support that someone may need?

Kate (42:05)

I think in terms of, after giving birth, but perhaps sometimes patients are still having treatment. It's remembering kind of the bigger picture of what's going on, almost as the kind of oncology, haematology team. It's easier to look after a patient once the baby is born because we only now have to consider one person, but it's not always that simple. Ellie had her baby and they were both doing really, really well very early on. But I've also looked after women who have had their babies early and their babies are in the NICU. And even if they're not in the NICU, you're in having chemo and your baby is at home. So you have that whole additional worry of who's after your baby and the kind of responsibilities that they have. Just because they're no longer pregnant doesn't mean that the responsibilities and things like that change significantly for the person that you're looking after. So, I think you need to kind of be aware of everything that's going on, checking in. I think just with pregnancy in itself, you give birth and everybody is like, this wonderful baby and the baby and the baby and the baby. And so I try and be like, like Ellie said, but how are you? it's very easy to be, you know, I'm fine. The baby's here and I'm happy because they're healthy. But actually, how are you? Because it's lot all going on at once and yet you happen to leave the baby to come for treatment and things like that. So it's, it is still again, looking after thinking about the bigger picture and looking after everything that the patient's got going on, still managing appointments and things. There are less appointments because you don't have the obstetric ones, but then you may, like I say, you might have a baby in NICU. And then, whilst treatment finishes, and I think I've said this to Ellie before, is that any patient going

through cancer treatment, we always talk about psychological support and do they require any extra support? And I find in my experience, a lot of the time when people are going through the treatment, the answer to that usually is no, they don't have the space or the capacity to process what they're going through and what's happening to them. But then you have your last day of chemotherapy and we take your PICC line out and we say, we'll scan you in six weeks and we'll see you after that. So we'll see you in eight weeks time. You know, we've seen you twice a week for the last four months and now we're going to see you in six or eight weeks time. And so I think a lot of patients feel abandoned. I don't know if that's the right word. A lot of patients feel like they, the support kind of falls away. And I think, from family and friends, and I don't think any family or friend ever mean to do this, but again, they see that, you finished your treatment, your line is out, you're not going to chemo anymore. You must be better. And people stop asking as much, how are you doing? Can I do anything to help you? Is there any support you need?

So as healthcare professionals and just, family and friends of somebody that's gone or going through cancer is to remember that just because the treatment has ended doesn't mean that they're better, doesn't mean that that journey is over. And in my experience often, that's the time the patient will sit there and think, what have I been through? And it's one of all of those emotions because they've got time to think about it. They don't, it's fight or flight, isn't it? And you choose to fight.

And so you get on with it and you put one foot in front of the other and you go to the next appointment and the next appointment. And when suddenly they're all not there anymore, I not from a personal perspective, but from what speaking with patients, they'll tell me that a lot that's where a lot of the psychological support. That's the time where you need to say, right, just remember we're here. This is the support that's available. This is how we access it. Please reach out because I think finishing treatment.

There's again, so many kind of things to go through and emotions and things, but as a healthcare professional, I would always say to people is that that's the time we need to be mindful that that just because treatment is ended doesn't mean the support should and maybe sometimes the support should increase really. So yeah, that's what we can kind of do better. I'm in our patients with the kind of resources that they need to find the support and to reach out if they if they're feeling like that

Emma (45:47)

Ellie before we ask you the same question Kate I just wondered from a resource point of view is there anywhere that you would sign post healthcare professionals to learn more about supporting someone during pregnancy and cancer are there any particular resources or information for professionals?

Kate (46:04)

So we use a lot of charities in terms of kind of support for patients. So Ellie already mentioned Mummy's Star and that's the only kind of pregnancy charity. There's also another charity. It's called the Fruit Fly Collective, and they are not they don't focus on pregnancy, but they focus on parenting with cancer and they actually do a lot of resources for health care professionals. It's where we get a lot of our you can get like cancer cloud boxes and things like that that we would give to families to give to young children to explain cancer. And actually, that's a really useful resource for healthcare professionals if they're supporting parents or new parents through cancer. It's the two kind of places that I would say have really good resources for healthcare

professionals to kind of help them support. And a lot of these patients are also young patients, obviously they're pregnant so depending on the age of the patient, but the Teenage Cancer Trust offers a lot of support as well, depending on the age bracket of the person you're looking after.

Ellie (47:02)

Macmillan have a cancer and pregnancy booklet that they've done with Mummy's Star as well. it's got loads of loads of information in it. So, I imagine that'd be helpful for healthcare professionals as well, 'cause it's like quite in depth.

Emma (47:14)

Thank you

Paul (47:16)

Brilliant, thank you. And Kate, thank you for all of that practical advice that you're able to share. And Ellie, is there anything else that you'd like to add?

Ellie (47:27)

I think what Kate said about the once you finish the treatment is by far the hardest part mentally. I thought of it like a cliff edge, like you it's just like everything drops off and you're just left with your own thoughts. But you've also got like when you've I've also got a baby to look after and I want to be normal. the treatment's done, you want to be a normal mum now, whatever that looks like. And you start trying to go and do normal things like go to a baby group and go to things like that. And that's really, really hard because you're you don't feel normal. Like I look different. I'm bald and I feel like I s you stand out, but I don't want the cancer to be my identity. But also, you listen to everyone talking about new mum things and thinking, I'm not worried about that.

I've got my PET scan tomorrow and I'm not gonna able to hold my daughter for twenty-four hours. that's my worry. and it's very hard to fit back into normal when nothing is normal yet. And it'll probably take a very long time and my new normal will be different. But this bit has been way harder, and Kate's told me loads of times that just be ready, be ready like it will hit like and I kind of knew that because you can't not process what I can't not be upset about what's happened. But the bit after treatment has been like really, really tough because you've got the emotions of having a baby and being at like postpartum. and also, like people don't drop off. People are still checking in, but you've not people would I'd have everyone message the morning of chemo, like say thinking of you today, and I've got lots of friends and family and they do still check in, but it's not I think I feel the pressure to be okay again as well. It's not necessarily them. It might be my own pressure of thinking, everything should be fine now, but it it's not. And then there's all the mental things of the side effects of chemo, lasting effects, fertility, all of those things that you at the time you sign the consent form and you're like, I've got a little bit of neuropathy, it's getting better, but will it ever go away? Will my fertility there's all these other things that you're like processing and that in itself would be stressful but having a baby to look after and then looking at baby and then there's still uncertainty and like what will happen in the future. it it's just really, really hard. it's not all hard, like still good days, but I just didn't appreciate how difficult it would be.

Paul (50:01)

I think it's really important there to acknowledge that, the new normal and still the changing priorities. I think it's so powerful, Ellie, listening to your side of the story as you navigate all of these challenges and we can't thank you enough really for sharing how it felt for you. And as we come towards the end of the episode, Ellie and Kate, I'd like to ask you what would you like listeners to take away from this episode? and Ellie, can I come to you first?

Ellie (50:34)

Yeah, I think one thing is when you're looking after someone who's got cancer and pregnancy, you're not just looking after someone who's a cancer patient or someone who's pregnant. Like you've got someone who's got the most devastating thing that's likely ever to happen to them alongside the most exciting, happy time. And that's really, really hard. and the other thing is that the conversations that I've remembered the most, not necessarily about the information or what someone's told me, but it's how someone's made me feel. So that's those are the people I've remembered throughout my journey.

Paul (51:12)

Yeah, thank you. And that and that's that that's really, really powerful. And Kate, if I can ask you the same question, what would you like listeners to take away from this episode?

Kate (51:23)

So that it's possible to effectively deliver treatment to a patient who is pregnant safely and for there to be positive outcomes. It is more complex, it is more difficult and you have to do it as a team. It has to be a multidisciplinary team approach but at the centre of all of that is a person who like Ellie said is going through the very worst time in their life simultaneously with what should be the most exciting time of their life. And so, you know, they are the key to everything, every decision that is made revolves around that person and that, what's best for them. And I think, you know, it's difficult, but it's, it's really, really rewarding. And, I got to meet Ellie's daughter and as a healthcare professional, I can't tell you there is nothing that gives me more job satisfaction than when I got to meet that healthy, beautiful baby girl and to know that Ellie was getting towards the end of treatment and how amazingly well Ellie did. She should be so proud of herself for everything that she's gone through.

Ellie (52:24)

Thanks.

Emma (52:26)

I don't think I can top that at all, Kate. And I just wanted to thank you both because today's conversation has really shown how a cancer diagnosis during pregnancy brings together two such life-changing experiences in a way that so few people ever expect and the real importance of compassionate and coordinated care, which sees somebody as a whole person and not just that diagnosis. And I think what really has resonated for me is that we've really looked at how professionals can support somebody through a diagnosis and treatment from those kind of small practicalities about appointments and trying to align those to as few journeys to the hospital as possible and that real value in collaboration and the conversations that matter most during what can be an incredibly complex time for everybody. And that really powerful reminder that you've both shared that support doesn't end when treatment finishes or when a baby arrives, that for many people those emotional and practical challenges continue long after

those milestones have passed. So, I wanted to say a huge thank you to you Ellie for sharing your experience with such openness and honesty. We are really grateful for you joining us today and Kate for sharing your experiences, your insight and your expertise so openly. So, thank you both for joining us on the Cancer Professionals Podcast.

Kate (53:54)

Thank you.

Ellie (53:54)

Thanks.

Paul (53:56)

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Emma (54:24)

If you enjoyed this episode, follow us so you don't miss our next conversation. We'll be heading to the UKON's Conference in Glasgow for a special live recording of the Cancer Professionals Podcast, where we'll be joined by Donna Bruce, Macmillan Programme Manager for Improving the Cancer Journey in Lanarkshire, to explore how taking cancer support beyond healthcare settings can help reach people and reduce inequities.

Paul (54:47)

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Emma (55:01)

I'm Emma.

Paul (55:03)

And I'm Paul and you've been listening to the Cancer Professionals podcast by Macmillan Cancer Support.