**Podcast transcript**

**Series 2, Episode 6: Infertility, miscarriage and baby loss**

**Opening credits** ‘Talking Inclusion with’ Steven Copsey.

**Steven** Welcome to ‘Talking Inclusion with’ from Inclusive Employers.

I'm Steven Copsey, Senior I&D Consultant and CMI Programme Director at Inclusive Employers and today we're going to be talking about fertility, miscarriage and baby loss.

It's important to note that these topics are often difficult to talk about, and some people may find it difficult to listen to this podcast. But no matter how difficult, it's our role to raise awareness and offer advice so that organisations can take action to support their employees.

And no matter how large or small your workforce, it is extremely likely that some people will be affected by fertility related issues.

Before we get started, in case you don't know us we're Inclusive Employers. Our mission is to make every workplace an inclusive employer where every colleague values differences and could contribute their skills and experiences fully to their organisation. These podcasts are for anyone who has an interest in inclusion and diversity.

In our podcast, we share life stories and experiences, learn about best practice, and hear practical advice for employers from our guests, as well as Inclusive Employers own inclusion and diversity experts.

Today for the first time I'm joined by three members of the Inclusive Employers team.

We have Jenny Smith, Comms & Marketing Manager. Hi, Jenny.

**Jenny** Hi Steven

**Steven** Jilly Svikis, Head of Comms & Marketing – Hi Jilly.

**Jilly** Hi, Steven

**Steven** and Rosie Clark, Head of Inclusion & Diversity North. Welcome Rosie.

**Rosie** Hi, Steven.

**Steven** We're going to start our podcast by talking about infertility. Fertility treatment is on the increase with around 68,000 treatment cycles carried out every year in the UK.

So Rosie, can we start with you? Euan, your child, is now one, what was your journey like to becoming a parent?

**Rosie** Long, Steven… long - Much longer than I was ever expecting it to be. So me and my husband decided that we wanted to start a family, and if I'm honest, I just thought, okay, you know, I know how the biology works, that's fine. Let's just do that. We didn't actually have Euan until two, two and a half years later.

In that journey. We had two losses, two miscarriages, on the way which I'm sure we'll touch on later, but I wasn't really prepared for any of that.

Obviously I knew that miscarriage existed, of course I knew, but one you don't think it's going to be you. But also I just thought, you know, two people make a baby and have a baby, and you know, nine months later, the baby's there. Like I hadn't really thought it through. Maybe I should, maybe I shouldn't, I don't know.

But you know, we're very, very lucky to have Euan now, and yeah, he's 18 months old now and terrorising our lives as you can imagine a toddler would be, but it has been a very difficult journey to get us to this place.

**Steven** Jilly, what about your experiences? Can you share with us how it went for you?

**Jilly** Yeah, sure. Like Rosie, it was a bit of a long journey to parenthood for me and my partner. And I think, really, when the doctor told us that we had fertility issues and needed support to have children, it was almost a relief. Because we'd had that month by month of trying and failing to get pregnant that I think we thought well, at this point, we'll actually get some support, and we'll be able to move forward.

And I think like many people who have fertility issues, it was at a time when many of my friends were getting pregnant. The baby announcements were coming in thick and fast. And while we were happy for people, it just made it really difficult, and it did sort of reinforce that we were the ones that weren't able to have a baby.

And I remember things like going bridesmaid shopping with my sister in law about 18 months before her wedding. And I was secretly thinking to myself, ‘well, I won't be able to fit in this dress, I'll either be pregnant, or I'll have a newborn’ and then 18 months rolls by still not had a baby. Another couple of years goes by, they had a baby and we still didn't. So it was just a very difficult time.

And I think that time had quite a profound effect on me. Without meaning to I started avoiding friends it was sometimes difficult to talk about it. I think it was difficult to know what to say because the same thing was happening again and again and again, and I couldn't get out of my mind so I found it really difficult to hold normal conversations and enjoy myself and have nights out.

Those things like lifestyle changes where I wasn't drinking anymore, meant nights out became different, even made them not enjoyable because everyone else is drunk and you're not, it just made it a bit too much like hard work.

Just things like we couldn't book holidays, because we might start treatment soon, or maybe we would be pregnant. So it just felt like I didn't really have a lot of control over my life at that time, it was sort of all consuming really.

And from a work point of view, I'd always been really career focused. It was sort of work first at that time, socialise at the weekend, and it was quite a social job as well. And at the beginning of all this, I think work was really like my sanctuary. It was a distraction from everything else that was going on. So I just got on with my job, people wouldn't have known what was happening.

And then there became a point when I did have to speak to work about what was going on. And that was at the point where we had to start IVF treatment the first time.

**Steven** You mentioned that work was a bit of a sanctuary for you Jilly. This is a question I have for both of you, actually, Rosie too, but did you feel supported by work, or was it just a place you went to busy yourself?

**Jilly** So work was a distraction, I didn't tell work until the point when I needed to, and the reason I needed to is because I needed that support to attend appointments.

When you're having IVF, you have a lot of sort of 15-20 minutes appointments, but with the NHS, you'll often have sort of two or three hours, waiting time for those. So it actually takes sort of an afternoon off work for each one of these appointments.

My line manager was supportive, but we worked in an environment where there was no flexible working, it just wasn't heard of really apart from the odd woman -and always a woman - who sort of worked 4 days part time because of childcare reasons. So it wasn't that environment where we had that sort of flexi time, you were expected in the office basically, and to be very visible.

And I think really, I put pressure on myself and nothing to change at work, rather than work doing that, for me, during things like injections, I just went off and did it in the toilets. Nobody really knew what was happening.

We didn't talk about things like infertility or periods, or menopause or anything, they just weren't things that you talked about, even with colleagues that were friends. So I certainly wasn't going to start talking about, you know, egg growth and womb lining and all those kinds of things that come with infertility and fertility treatment that are difficult to talk about.

Because with infertility, people don't know what to say to you. So when people do say things, it's often my uncle's friends, dogs, cat had struggled, they struggled to have a baby, and once they stopped trying, they got pregnant, and it was that constant. That was the response that you got when you tell people that you were having treatment. So it became easier not to really talk about it.

**Steven** And Rosie, thinking about your support in the workplace, was anything specifically put in place to help you through that time?

**Rosie** There wasn't anything specific, but I suppose I have been really fortunate that I've been here at Inclusive Employers a long time now, and my whole pregnancy journey has been as an employee here Inclusive Employers. So really, what better place could I be, and I realise I'm extremely fortunate to have had that.

But I think a lot of the barriers came from me rather than from the workplace, partly because there's not that much your line manager or your colleagues can do. They can't help you get pregnant, you know, like, and ultimately, that's what I wanted to do. So all they can do is make you feel comfortable to talk about it if you want to.

When I had my first miscarriage, I didn't actually tell anyone, even though I work here, which you could say, you know, is the best possible place to work, I still didn't actually tell anyone. And when I reflect back on that, and I think like, you know, what could have people have done to make me feel I could tell them, actually nothing. Because I didn't have the language. I didn't know how to tell people. I was so shocked by it. And so, it's so biological.

My first miscarriage was what they call spontaneous. So I was pregnant. I hadn't told anyone I was pregnant. I was only six weeks - I'd literally just found out like a week earlier, and then I started having really strong stomach cramps. And I was just driving back from a meeting in Yorkshire and I had to pull off the road because some of the cramps were so strong and I was like, it was like dangerous to drive a car. And I went into a fast food restaurant toilet, and obviously was bleeding and didn't know what to do. Obviously crying my eyes out, wondering what was happening and buying the doctor and all that stuff and they obviously confirmed that I was miscarrying, but I called in sick. I said I wasn't feeling well. (I) called in sick because I just didn't know what to say. And, my line manager is amazing, she couldn't be better, she couldn't be more supportive. But I still couldn't tell her. I also didn't want people to know I was trying to get pregnant.

And that's the big thing, I think when people tried to get pregnant, and they do have something, like a miscarriage, often they don't talk about the miscarriage because ultimately, that's outing themselves as someone trying to get pregnant. And I just didn't want people to know it, because I didn't want people to ask questions…

And I know, again, this is my issue. I know that my line manager wouldn't do this. But I didn't want people to have in their mind, ‘Oh, she'll be going off soon. So like, Don't give her that project. Don't give her that she'll be going off soon’ as it even if it was subconscious, I was worried about things like that.

It was very different the second time around, because I had already told my manager at that point that I was pregnant, and I had at the time I told her I was pregnant. I'd also told her, by the way, I also had a miscarriage earlier on in the year, she was upset that hadn't told her obviously, she was like, ‘why have you done this alone’. But she understood, but then when I miss guide, the second time, it was later on in the in the pregnancy at 13 weeks. So everyone then did know, because I was off work for quite a lot of time... Or a few weeks, it wasn't that long.

So yeah, it got I think, the more horrible experiences I had, the easier it was to tell people at work and to talk about it. But ultimately, I think apart from just being there for someone to talk to, there isn't a huge amount that a Line Manager or colleagues can do. It's just giving people the space and also accepting this, I don't want to discuss it.

**Steven** And I think that's a really important thing you've mentioned, that even in this working environment with the people that you are working with, who you can pretty much tell anything, even you did not feel like you wanted to talk about this, or could talk about this, being able to talk about this today, I think it's gonna be really powerful. It's going to allow people to maybe make that connection, maybe talk about some of their past experiences too, that they've not felt comfortable or been able to talk about.

**Rosie** I have found talking about it now… It's been really healing for me in the past, but I couldn't talk about it at the time. And I think y’ know, there's the old phrase isn't there ‘time is a healer’ and I think that's been really true in my case. And obviously, it's different.

I couldn't talk about it at all, whilst I was pregnant with Euan, because the worry was just like all consuming. But I do think that at some point all like employees will get to a place where actually talking about it is really helpful for them, and having some places in the workplace where you can talk about it, even if it is I had a miscarriage 10 years ago, you know, it doesn't need to be raw in that sense, then whenever people are ready, it really can be healing for them to do so.

**Jilly** I think you're completely right there - people have got to find their safe place to be able to talk about these things. And it's probably not likely to be work at the time that this is going on, and some bigger organisations may be able to form networks where people can share their experiences and support each other. But for me, I wouldn't have probably wanted to take part of that. And I think there's a couple of reasons.

One is, like Rosie, I didn't want to disclose the fact that I was trying to get pregnant, I was worried about the impact that would have on my career. I was very serious about my career, and it's hard enough telling an employer that you that you're pregnant, and that's going to inconvenience them. And you know, you feel like at that point, it's going to have an impact on your career and your career development. So telling them that you're having fertility treatment, which may take years, you feel like that could be years behind on your career, no matter how hard you work.

And on the other point, having a support network. I couldn't find support at work. I didn't try to, to be honest. And I couldn't find support within my friendship group, and so I found a new friendship group of people were having treatment the same time as me, and that really helped me because we were able to talk really candidly about what was going on.

We met fairly regularly face to face and could just get advice from each other, chat through what was going on, but it was also a very positive group. So we weren't there dwelling on all our problems, we're actually trying to support each other through it. And when each of us got pregnant or adopted wherever their path was, we were really happy for them. We had baby showers and that kind of thing. So it was a really nice positive experience which I was unable to find in other areas of my life.

So my eldest child is 10 now, so this is going back kind of 15 years really when this all started, and they're still sort of my close friends now we still speak regularly and meet up when we can. So that was just a really important thing for me to have that. But it wasn't to do with work. And that was my choice, I wouldn't have wanted it to be a work related thing.

**Steven** The Miscarriage Association say that one in four pregnancies end in miscarriage, which affects somewhere between one in four, and one in eight women.

Jenny, let's bring you into the conversation now. Thank you for joining us today. Can you tell us about your experience with miscarriage and baby loss?

**Jenny** So I had a miscarriage. My first pregnancy I had a miscarriage. And that was about I suppose maybe 18 months ago, I think I was about seven and a half weeks pregnant, and started sort of getting some bleeding. And I was really anxious when that happened. But I spoke to the GP and they said, ‘Well, you know, you can get some spotting and pregnancy, it might be fine’. And they weren't, I think, because it was COVID and lockdown, they weren't really in a hurry to see people in person. So they just sort of said, see how it goes. And then it didn't stop.

So I spoke to the early pregnancy clinic, and I remember them telling me to go home, take a pregnancy test. So I was at work at my other job that morning. So I did, I stayed at work for the morning. And then I sort of had to make my excuses because I say similar to what Jilly and Rosie had said.. I didn't feel like I wanted to tell anyone that I was pregnant for all the reasons.

Things did get worse. So we did manage to get a face to face appointment with early pregnancy clinic. And again, another positive pregnancy test. But then we had a scan, and then they did confirm that there was no heartbeat. And I remember the nurse saying afterwards, ‘Do you want me to write you a sick note’?... ‘Do you want me to say the reason why’? And I hadn't really thought about having any time off work, I suppose I didn't really know. It all felt like a bit of a blur. I didn't really know what was going to happen to my pregnancy, to my body. And I don't actually remember whether I said right miscarriage. or not to be honest. But I did.

That was on the Friday. And I'm thinking I'll be fine today so you can. But then when Sunday came, I thought no actually I just need some time, I suppose I felt very supported by work, I think I was encouraged to do what I needed to do. I felt really grateful for. for that. And I think like Jilly mentioned earlier, the safe spaces are so important. And I did feel like that was given to me by work.

And then my second pregnancy, we did get pregnant relatively quickly after the miscarriage, and the first I suppose 10 weeks or so of that pregnancy, were very nerve racking. I didn't actually do a pregnancy test at about nine weeks, I think because I knew that I'd done this before and got a positive result when I was having a miscarriage. So it didn't really feel like any certainty, you know, just to see those lines doesn't mean happy days for the rest of your life.

So then we did get to a stage where we felt more comfortable and got excited, had a happy 12 week scan. So we went for our 20 week scan, and the sonographer… I could tell she was really concerned, and weirdly, it was the same sonographer who confirmed that our first baby's heart stopped beating. And I remember saying, ‘it's very nice to see you in different circumstances’. And that felt really weird when we did finally leave that appointment.

So our daughter was, the sonographer confirmed, she was very tiny. She said, She's the sort of size that we would expect to see it maybe 16 or 17 weeks. And I don't remember exactly what she said, but I remember her saying.. I remember the feeling was bad. I remember leaving the room thinking this is very serious. I don't think this baby is going to live.. I don't really know. I don't know, everything just stopped I suppose.

I do remember her saying you can still get maternity leave after 24 weeks. And that sort of like kept playing in my head afterwards. And that was the almost like the confirmation for me that she was thinking that this baby wasn't going to live.

So we then we got referred to the foetal medical unit, they can do more detailed scans, and that was a week later. And they confirmed what the sonographer feared, that our baby was very small, and that was sort of, I suppose in the beginning of quite a… it felt quite torturous, I suppose sort of seven.. it felt like months, but I think it was actually about seven, seven or eight weeks of, we both had to go to the foetal medical unit every week, because in the initial appointment with them, they told us that they did confirm that they didn't think our baby would live. And they said, you know, when you come back in a week, you should be prepared that like the heart might have stopped beating.

We weren't back then the following week. So I suppose, like 22 weeks pregnant around, and our baby was still alive, and this then continued for about six weeks. I remember one scan, the consultant said, ‘I think maybe she'll live between three days to a week’. And every time we went in, and she was still alive, I sort of felt that she was. So yeah, it was just really the most surreal time of these weekly scans, we're sort of essentially waiting for our baby to die, which is just really horrible… but it was sort of our reality of so strange that that's sort of what we were doing.

We had been well advised. No one had given us any false hope. I remember my dad saying, ‘Why are they putting you through this, if this baby isn't sort of a miracle is there not another way they can do this?’. And I suppose that would be the option to terminate for medical reasons, but it felt for us that sort of, I suppose letting our daughter like live her life to the end. It sort of felt like what we wanted to do, I suppose.

So then we did have the final scan, and the consultant confirmed that her heart had stopped beating, and I say like death, even when you know it's coming, it doesn't make it any easier.

And so throughout this sort of period of seven weeks, I suppose because every week, we had maybe even thinking that she wouldn't be living anymore. We sort of be mentally preparing for... for labour, there was so many things to be scared about. I was very scared of having to give birth and my baby that was dead.

So after they had confirmed that our heart has stopped beating, they prepared me for labour with some like tablets and the few days before and then I went into hospital. Just like any other normal labour apart from the, like, huge difference. I knew my baby wasn't gonna be born crying and breathing.

It feels really strange for me to say now but my I was so scared of meeting my baby that had died. I remember asking the nurses like what you know what to expect, or she looked like, it still like blows my mind like she was 250g when she was born, and so tiny, I thought of like a bag of sugar. I like baking. So I sort of that's how I relate it in my head.

People perhaps don't realise that a lot of the experiences that you have in pregnancy, when it doesn't go right are very similar to what happens in a pregnancy that does go full time with a living baby.

You still, like my body still thought it was gonna feed a baby like I still have breast milk like all of those things, but no baby to feed and so really, yeah. That's a lot.

**Steven** Thanks, Jenny... And Rosie, you talked about some of your experience. Can we revisit that, but also, what impact did it have on your husband, how did that go, and what was it like? I guess is that is the question.

**Rosie** Yeah, absolutely. You know, asking about my husband is a really, really important question itself. Like, as much as you know, I'm happy to share my experience. I do think partners, non birthing partners are forgotten about often in these conversations. You know, it does have a very different impact on the birthing person, as it does on the birthing person's partner, but it's still an important impact and they're still important people.

I think you know, I've mentioned my first miscarriage was reasonably early, it was my first pregnancy. My second one, slightly similar experience to Jenny and the fact that I found out at a scan. So I went in for my 12 week scan at 13 weeks at the time, and was told there that my baby didn't have a heartbeat or my baby's heartbeat had stopped, at some point. I had to make a decision… On that day, what I then wanted to do about this baby that had died, and I didn't know anything about any of the options. They walked me from the.. I can't think of whatever the technical word is, but the place where they scan you in the hospital, where there isn't just people being scanned, babies being scanned, as well, there was lots of other types of scans happening. And they walked me through the hospital to like a pregnancy unit, which was in another place,

I was screaming, hysterically screaming, and there's people just pushing their newborn babies past me and all this stuff that really, you know, didn't help in the circumstances.

And then I was put in a little side room, my husband was there at the time and given a pamphlet, and said, you know, here's your options for essentially, you know, they talk about removing the tissue, which I don't like the language around either. And you basically have three options. You see what happens with biology, and you kind of let it be, but nothing might happen. Or it could potentially take months, like you just don't know what your body's gonna do. You take some tablets that force your body to miscarry. Or you go in and have surgical procedure to remove the baby. And this is literally 20 minutes after I've just been told, and I'm having to make this medical decision.

So off I went for these tablets the next day, and I suppose this is where my husband's experience really comes into it, which is that he was basically invisible. Like nobody spoke to him, nobody… I don’t think anyone had eye contact with him, nobody acknowledged his existence. And he was there with me, though, obviously, it's my medical records and stuff. So they would obviously call me, but he was there with me. Nobody asked his name. Nobody even asked him like, “Are you the birth father?” You know, it could have just been my friend for all they know.

But I am dyslexic. So I struggle with reading like physical paperwork. So I was like, ‘Oh, could you just give him the paperwork’, and they let him read it out to me. Not that it would have made a difference, because I would have signed it regardless. Because again, I didn't have the capacity. But because of being dyslexic as well, I really didn't have the capacity. So he read it out to me because you have to sign… Well, I don't know, I don't know what I signed. But I signed my life away essentially, to something to say I'll take these tablets and I deal with the side effects I assume.

Took the tablets, they said they'll take up to the user take up to 48 hours to stop. But they can take longer, but essentially give us a call if nothing happens in 48 hours. So off I went home, just sat there waiting to miscarry because I also was visibly pregnant. So I'd got bumped quite early. And I was just sat there kind of walking at my stomach and sort of knowing that the baby wasn't alive anymore. But waiting for something to happen. Nothing happened. So after 48 hours I rang, and I said nothing's happened. Like I'm still I have not bleeding or anything. And they were like, right, okay, well, you'd have to come in and have this tablets again, that always work the first time round.

I went back in on the Monday and I think day five, it must have been on the Monday had them again, went home. 48 hours later didn't work. Rang again, I'm still this is like over a week after I've been told that my baby didn't have a heartbeat. And at this point, I'm still pregnant. And I was just like, the tablets haven't worked again. I'm still here. And they're like, “Okay, you have to come in and after surgical option.” So I went into the surgery route, all in all it was two weeks from from being told that we have no heartbeat to actually the baby being removed through the surgical options. And, then you go home and have a bit of recovery, of course, because it's general anaesthetic.

And yeah, again, nobody knowledge my husband in any of the appointments. When we went in for the surgical option, nobody spoke to him, nobody acknowledged his existence.

As a whole experience, it was lacking in humanity and understanding people at all. And I kept having to, obviously ring work and say, I'm still pregnant. I'm going in again, like, because obviously, my workplace was very understanding. But I guess when I originally told them, they were probably expecting me to have maybe a couple of weeks off. But two weeks later, I actually was still pregnant. So I was clearly then going to be needing more time off. So it was quite difficult having to then communicate that back to the workplace, and, then sort of go, well, I guess I'm gonna need more time, I don't really know how long this is going to be. And my husband, again, was, because he wasn't the one going through it, but he obviously still lost his baby. Like, he was really I guess, removed in the sense that he was having to communicate with his workplace, what was happening to me and feeling a bit like, how much do I disclose because it's not his body, it's my body. And you know, we understand that. And so I think that was probably quite difficult for him.

And one thing that really helped him is that he started writing things down, and not sharing them with anyone, but just writing down what had happened, how he felt, he is a politically active person. So this might be a weird, sort of a weird way to help yourself for some people. But like, he wrote to our MP about our experience, just explaining and making some suggestions about how the support for miscarriage could improve. He wrote to the hospital, so it didn't complain that he wasn't complaining. And he wasn't asking for anything. He was just his way of, I guess, doing something with the emotion or the experience was to be active with it.

So he wrote to the hospital as well, and yeah, I think that kind of helped him. And he also kept like a bit of a journal, I guess, of how I was feeling. And he eventually posted a blog online about his experience.

For men, we know that men's mental health is a big issue in society, because of them not feeling that they maybe can talk about it. But also for same sex couples as well. There'll be unique challenges that they will be going through. And I guess there's probabl,y I mean, I don't know, as I'm not in a same sex relationship, but I doubt there a specific help out there for miscarriage in same sex couples. Because if there isn't for straight couples, there probably isn't for same sex couples. So, you know, there's there's a lot lacking in the infrastructure around supporting people.

**Steven** Jilly – How about your experience, how did it go for you, and how was that managed alongside work?

**Jilly** Well, my miscarriage was after my second IVF attempt. So it was the first time we had successfully got pregnant, which had come after years and years and years of treatment and trying. And when you have IVF, you have what you call your two week wait, and that's the period in which you are pregnant, because you've had an embryo transplanted into your body. So in theory, you are pregnant, and you have to wait two weeks before you do a pregnancy test to see if that baby or that embryo has survived the transfer and is growing inside your body.

So following this two week wait, it was the first time we had the positive pregnancy test. So it was just a huge relief, I think, you know, we'd finally got to the point that we've been striving to get to and the build up had been so great, that when that pregnancy resulted in miscarriage a few weeks later, it really did hit me hard.

Similar to Rosie in that, obviously I was at work, most of the week is spent at work, when I started bleeding. And unfortunately for me, I had a meeting with a client that afternoon who was just returning back from maternity leave. And it was just as I was about to leave for that meeting with my manager that I realised I was bleeding.

And like Jenny said earlier, you know that spotting is common and so I was trying to convince myself that we got to the and my clients workplace, I went to the toilet again, realised “No, I don't think this is just spotting”. And I should have been stronger in that instance to say I can't do this meeting. But I did. And I spent the meeting listening to how this person, who had obviously had no idea what was going on, was moaning about their newborn baby and wasn't a newborn, it was a year old, returning to work and how difficult that was. And I remember just sitting there sort of dying inside thinking, this is just such an awful position to be in,

I think, listening to sort of Jenny and Rosie’s experience that it's made me think, well, maybe I haven't processed what's happened to me enough. I just remember feeling completely, you know, devastated thinking about right, well, we've got to this point, but it's still not worth it. So what's next for us? What do we do now?

As much as IVF treatment or miscarriage, have such like physical impact on your body? I think it's the emotional and mental impact, that you really have to think “Can I do this anymore?” You know, “am I strong enough to continue with this?”

And with regards to work, because we'd have the IVF treatment and taking the time off for that, I felt like I couldn't really take much time off the miscarriage. So I don't think I really took any time off. I think I was just straight back into work.

**Steven** So this is an open question to you all. And I'll go to each of you in turn. But what do you wish more people knew about your experience, and is there anything that you would really like your colleagues, but also they're listening to to understand about your experience? Jenny, can we start with you?

**Jenny** I think there are lots of things. I think just having this conversation between us all is amazing. Because one of the things I found really hard last year, or the end of last year, it's just the loneliness. And I sort of am aware that people don't really know what to say, but the lack of awareness of all the different ways you can struggle to be pregnant, struggle to stay pregnant. It's overwhelming. I think that I always remember, when we had our first miscarriage, I didn't really know very much about miscarriage at all. The only reason I knew what I did know, was because I had proof read the increases employers daily loss and infertility guide, only two months previously. And I've just felt so grateful that I had read that because I just meant I knew a little bit more than I had done previously.

So I think the more conversations, the more openness we can have. A few people have said to me, not necessarily colleagues, but friends and family y’know they just didn't know what to say. And I think, actually just, you don't need to have the right words, you just let people know that you're there, that you're thinking of them, that you're maybe holding space for them quietly, even if you're, you know far away, is really a great comfort.

I think another thing, and again, everyone will feel so differently about this and similar to I suppose what we were saying about the remembering of the babies and the family that aren't here, I sort of found it hard that people, or it felt like people sort of forgot or perhaps don't see me as a mother, and in my mind, that sort of invalidates my daughter's very short but ultimately extremely precious life.

And again, like with time, you sort of become more comfortable with these things. So, I suppose more confidence in public conversations about this kind of thing, I think would be really helpful for everyone. Because like I said, if I hadn't read that book or our brochure, I would have known so much less than I did, and I didn't know that much anyway, I just think the more sharing the better for everyone.

**Steven** Absolutely. especially when you know, if we are thinking about reading upon this, it's not a case of this is only for those people who are going to go through miscarriage or baby loss or struggle with fertility issues.

We can all learn about this. We're never going to know exactly what everyone's going through. We can't, it's impossible. But it might give us a bit of an idea of okay, what might they need from me? How can I show I’m there, if they choose to, to call on me? And also, you know, maybe a bit more of that process.. What does happen and why? Because in this whole inclusion space, if we're uncomfortable talking about something, we often try to avoid it. So if we can learn more, we can open up those doors and have more conversations like this Absolutely - Thanks, Jenny.

Rosie, how about you? What do you wish more people knew about your experience?

**Rosie** I would have liked people to have treated it like you would if anyone had died, and say like, you know, would you like to come out for a coffee with me? Or, you know, can we go for a walk, or here I've made your lasagna, you know, bring it round, like, don't give me options. Because I'm not, I'm not capable of making those choices. And obviously, you're not going to force anyone to do anything. But I would have gone along with whatever anyone suggest, and it probably would have been good for me, if someone had of any, you know, I did have some great friends and stuff who were really, really helpful and family members.

I guess, the other thing would just be that education piece, I didn't know anything. And as I've explained, I felt really lost in what to do and how to deal with it. And because there isn't really that much support through the kind of medical system, if people around me had’ve had the language, and could have had conversations with me, then I think I would have been able to sort of navigate through it, would have made it any less difficult, but I would have been able to navigate through it better, because I want to felt so alone in doing it.

And I think as much as you can read, you know, listen to things online, or whatever it might be, the better. And even if you are a person who never wants to get pregnant, or maybe is someone who couldn't get pregnant, still read about it, you know, because people that you love might go through this, and particularly anyone who is a line manager, or has aspirations of being a line manager in the future, like make sure you do have some understanding, so that if anyone that you're supporting is going through something like this, you can at least have a basic conversation, you know, just a bit of language, a bit of understanding of the process that happens when someone says I've had a spontaneous miscarriage or I'm having a medically managed miscarriage, like, ‘Do you know what that means’? Because asking them the questions probably isn't great in the moment. So yeah, I mean, I would say read our pregnancy and infertility guide, because I wrote it... But do read it, you know, and it's it is helpful, but I found ‘Tommy's - the miscarriage charity, baby loss and miscarriage, charity’ was really helpful to me. (www.tommys.org)

And I would advise anyone check out their resources as well, because they are really fantastic. They are a charity, it's all free. So it's a great place to kind of go and get a bit of education for yourself as well.

**Steven** And Jilly, how about you anything else you wish more people knew about your experience?

**Jilly** Yeah, I think I just like to add that we know that miscarriage and infertility are really common issues. But that doesn't mean that it's less devastating to the individual. So at that moment in time, they're going through a really traumatic time of their life. So that needs to be acknowledged.

I think it's common, unfortunately, I think you said at the beginning, Steven, it's one in four women will experience miscarriage. However, every experience will be different. And every experience is really important and valid.

Going back to what Rosie was saying earlier, there's very little support to people who experience miscarriages. I think when I was going through it, I was told that you have to have three before you got any additional support. Before you could even have a follow up appointment to discuss what may have happened…

**Rosie** That was the same for me Jilly - You had to have three before there was only support available. So after my second that was sort of like, right, well, one more I might get some help. Yeah, it was just like that was the goal then to like have another miscarriage just so I could get help, Yeah. So that is an obviously there's a time difference between you and I. It is still it's still the case. It's three..

**Jilly** …and it's still three. Yeah, so that hasn't changed, which is a huge amount. And it is a resource issue, I assume, you know, for the NHS because it is so common, but that doesn't mean that the individual doesn't need additional support. So any support you can give people while they're going through these issues will be you know, really, really appreciated.

**Steven** That's the thing as well, isn't it? You know, that's three separate instances of grieving to go through one after another, I assume is gonna build up on each other. So each one is going to be traumatic in its own right. But that buildup is gonna make things even worse.

**Rosie** And the people always I felt like the 1 in 4 stat, was like rammed down my throat when I was having miscarriages, because it's like people want it to tell me it was normal as if that was going to make it better.

But I always… and this just shows how people don't see it as grieving. Because imagine if your mother or father died, and someone went, ‘Well, everyone's mom or dad dies eventually’.. Imagine… people won't go ‘oh, well it's normal for your parent to die so please don't grieve it’. Whereas with miscarriage, telling me it was normal was somehow supposed to take my pain away, when actually what it said to me was, you don't understand my experience, and you don't see this as loss, you don't see this as losing a person.

And I do understand that for some people, based on their beliefs, or because this is the best way for them to deal with it, and that's okay. They don't want to think of it as a baby. Absolutely not a problem. That is their experience. That is fine. But if I think of mine, as a baby, than I expect to you to think of as my pregnancies as a baby, and therefore treat them as a loss of a person.

Because I did have a few people say insensitive things about like, “oh, well, least you weren't further along”, or at least, you know, all this stuff that kind of, as if it wasn't a real loss, because I don't know, like, for some reason, they didn't define it as as a baby. And that was really obviously unhelpful.

So although I agree that it's important to raise awareness of how common is just because it's common doesn't make it.. It doesn't mean we should normalise it or something we shouldn't feel an emotion about…

 **Jilly** Yeah, and invalidate people's experiences and feelings at that time, which a you just said, Rosie, that's often the response, unfortunately, a very human natural response. But yeah, that's one that's not not helpful.

**Jenny** I think that's something I found quite difficult. People - the human instinct to want to fix things. So it makes everything okay. And actually, you can't make everything okay. Sometimes you just have to be with it.

I remember someone saying to me after a miscarriage, at least, you know, you can get pregnant. And I remember stopping thinking, ‘Should I be grateful?’, like that I was pregnant… And now I think I know, it came from a place of care, but just really misguided. Yeah, sentences that start “at least” are just really hard.

**Steven** We have talked about support from employers, is there anything else that you'd want to mention from an employer support perspective, that they did for you that you've not had a chance to talk about yet – Jilly?

**Jilly** Not so much the support that I had, but my group of friends that were going through the same thing, at the same time as me, I've spoken to them about the support they got, because actually, it was something that we didn't talk about at that time, we talked more about what was going on with us, not what was going on with work, and I was quite sort of surprised to hear about the range of support they got.

So some people had policies in place, some had really great blind managers that were completely flexible and supported them every step of the way. Some just didn't tell work at all, and actually, for my fourth IVF, I had a different line manager and I didn't tell him at all, I only told him when I was pregnant, and I just managed it through taking holidays and that kind of thing, because I didn't have that trust in the relationship where I felt like I could even start to have a conversation about this. And part of it was about the career thing. And part of it was just a general trust and the type of relationship that we had.

Some of my friends had flex time as part of their role. So they were able to work around that. So all those flexible options really help across the board, various different types of people.

But I think what was common with everybody is that all said that the think things have improved for better in their workplaces, that more policies have been starting to put into place that there was more awareness of what was going on, alongside things like more talking more about menopause, it was also more talk about infertility and miscarriage and pregnancy general now, so that's a hugely positive change. I think over the last sort of 10 to 15 years that's happened probably not as quick as it should, but it was really nice to hear that that changes are happening.

**Steven** Rosie and Jenny, anything more you'd like to mention from an employer support perspective?

**Rosie** I do think a policy is a good idea. It will depend obviously on the size of your company, but either a bereavement policy that has a specific mention of miscarriage and baby loss. And I would, if you've got a bereavement policy, I would make a specific mention even if you have it a separate policy, or a separate policy on miscarriage and baby loss, and just sort of laying out the expectations and respects of like, as an employer, we will give you ‘x’, it's usually, you know, either either from a few days to maybe a couple of weeks, depending on the employer, but also some things in there about your manager being able to use discretion to support you to go to appointments or you know, those sorts of things like with, you know, pretty much all of our experiences in different pregnancies, we've had to attend hospital on multiple occasions, even when we knew that we were either losing or going to lose or had lost our babies, we've still in and out of hospitals, so like, I think there needs to be a policy that explains that it's not just a case of it happens day one, you go home, you have a week off and you comeback like because you're in and out of hospital, you know, lots of things are happening.

So you need a policy that has that kind of flexibility in there. I think that's really important, but also just kind of a note, and it does apply to all policies, but making sure that we're really, really gender neutral on the miscarriage and baby loss policies of the pregnant person, because, of course, you know, not using woman is the best option, just use in pregnant person or pregnant employee, you know, we obviously have trans non binary people who are able to get pregnant and carry babies, so we need to make sure are inclusive of them in that policy as well.

But with partners, there is the flexibility for partners to have some time off, it might not be as much time as the pregnant person. But there needs to be an acknowledgement that if your partner has miscarried, you have miscarried, I mean, you are part of this relationship. And you should be able to use that policy to have a bit of time off a fever and mental health and you know, support your partner if you need to, as well, so I would recommend a policy or some managers guidance around how to support people.

**Steven** And Jenny, anything from you from that perspective?

**Jenny** I think just something that I haven't shared about how it was supported, I suppose, after my daughter was born, and because I was because of the time scale of the pregnancy that she died, I did take maternity leave. And I've just feel very grateful that I've felt like I was really given a lot of space to return to work at a pace that I felt comfortable with. Jilly’s my line manager, and we were in touch quite regularly, sort of timescales that felt comfortable for me. So I felt like I knew what was going on.

At work. I didn't feel too overwhelmed. I remember, after I came out of hospital, both my managers asking me how I felt like coming back to work. And I just, I just realised I literally had no idea. I thought of like I couldn't really do any life stuff. Like functioning was not really something I knew how to do. And I think I could have said, ‘Yeah, I'll come back next week’. But I don't think that would have been good for me, I don't think it would have been good for any productivity levels at work. And again, like everyone will be different. I know some people who have appreciated getting back to work and have been distracted and being able to get on with things. But that's one thing, lots of things. But that's one thing in particular, I feel really grateful for.

When I did start to do more work like it was quite gentle. And then when I did come back to my full hours, I felt ready and sort of had been dipping my toe in properly for a while. So I think that was best for me. And I think for the work I was able to do as well.

**Steven** We've heard about how consuming infertility miscarriage and baby loss can be and how employees do need that support from employers during what is likely to be an extremely difficult time. We're just going to take a bit of time now hearing some advice, tips for employers, colleagues, to understand more about what we can all do to be more supportive.

So Rosie, we'll start with you. Do these topics come up often, with our members at Inclusive Employers that we work with, that we train with, that we consult with, and how do those conversations go?

**Rosie** They don't come up as often as I would like them to. But yeah, it definitely is increasing. So, over my time at Inclusive Employers, definitely in the first few years, it wasn't a topic we talked about at all. I mean, not that was brought up actively, we may have talked about it, but not that was brought up by members.

But I would say over the past, maybe two or three years, it is an increasingly talked about topic, and I think that is really in line with society that society is a bit more open to this discussion, and therefore, that's kind of filtering into the workplace.

But we really shouldn't be switching that on its head, if we're an inclusive employer, we should be the one driving societal change, right? That's our of all. So we shouldn't be waiting for society to decide that this is a safe topic, we should be making our organisations safe spaces for people who wish to use them as that.

And I do think some of the things that have tips that employers can think about is, are you a psychologically safe organisation, and that runs through all types of inclusion, as we know, and for those people who you know, use us to deliver training, I'm sure your facilitators have talked about psychological safety. But there's no way a person is going to talk about miscarriage, fertility or baby loss in a place where they're not psychologically safe.

So it's thinking about that in your organisation? Where are those spaces? Where can we hold safe space for people, it's also worth thinking about, if you have employee networks, which many of our members do is how can they weave this topic into the work they're doing? Now, naturally, a women's network, you're going to expect conversations around parenting and motherhood. But that's not always an inclusive conversation.

And as Jenny mentioned, earlier, you know, Jenny's had some experiences where, you know, people's expectation of what a mother is haven't been correct. So actually extending that and making sure that a mother is someone, well, itself define it in many ways, but is not always someone whose baby is with us, you know, it might be someone's baby who's passed away. So having that space, to include those people within those conversations and networks, is really important. But remember other networks as well, if you have mental health networks, this is a huge part of that.

If you have LGBTQ networks, you know, we know that for many LGBTQ families, they may have to use fertility treatments to start a family. So they are coming at it in a different way. And it might, you know, it's often a more positive way than maybe Jilly’s experience, that they're taking that step, but still, the eggs might not take, and they might have a lot of that loss that comes with those. So having those conversations there.

So really use the safe spaces that you have in those networks, and weave in some of these topics, you know, it is about us all being able to talk about it, not just one group of people, and often who society defines as mothers, which is isn't always correct anyway. So weaving those topics and having that policy as a guidance for line managers, you know, we put a lot of expectations onto line managers, to be able to support their employees in absolutely everything that kind of comes out them.

And not all line managers will know anything about this. As much as we want them to equip themselves with information as their employer, as their kind of HR or leadership function, we need to make sure that we give them some written guidance as well. or provide them with links to this podcast, of course, or, you know, webinars or charity websites, whatever's out there, so that they know where to go. And they don't make, you know, mistakes that are going to hurt people's feelings, because they're ill informed on a subject or they're panicking, because they don't know what to say, because they haven't been given the tools to do that.

So I would say education, policy, safe spaces through networks are the three key areas for me in making it inclusive workplace for miscarriage, baby loss and infertility.

**Steven** I think you bring a really good point with that network perspective, too. Because, you know, if we think about our race and ethnicity networks, too, they're going to be some communities, some cultures that handle infertility and miscarriage conversations very differently. Some will be more stigmatised than we are whereas others may actually celebrate that life that did not end up existing.

So actually, what can we take from those cultures? What can we bring into our own? How can we help those that are more stigmatised? Because our race and ethnicity networks are going to be so diverse in their ways of thinking about different types of miscarriage, baby loss infertility, we can't just approach it from that UK societal cultural perspective, because even we struggle with it, and lumping everyone into that box is is not helpful either. So yeah, absolutely right, bringing those networks in Rosie. Jilly, how about you any advice for employers.

**Jilly** I think what would have really helped me and my line manager, would have been a policy, I think Rosie said it earlier. But just having that guidance as to what she could do, and what I could do would have just provided a lot more clarity. So for instance, I know employers now have policies where you can have five days off during fertility treatment, just knowing that that was available, and therefore how you could use it will be really useful.

And I think there's just that understanding, and this is particularly with infertility, and treatment. timescales change, you don't have any control over what's going on. So often, appointments can be at short notice, you might have to have procedures at short notice, depending on how that treatment is going, so having that flexibility and that awareness around, people will be trying to give you as much information as they can, but sometimes they'll be given a phone call, and it'll mean that they have to have a procedure the next day. And then that procedure may go one of two ways.

So just having that flexibility around that time would be really, really useful and helpful for people and just having that safe space where people can tell you as much as they want to tell you, you don't need all the details. But you just need to have that trust in your employee that they're going through a really difficult time. And having just that flexibility would really would really support them through it.

**Steven** And Jenny, how about you - Any advice?

**Jenny** I think the only other thing I would add to what Jilly and Rosie have said, is that we haven't the inclusion passport at Inclusive Employers, and I have found that quite useful tool, since being back to sort of highlight some things perhaps that I feel more sensitive about. And I suppose it all links back to what Jilly was just saying about having an environment where there is trust and safe spaces. I'm really grateful that we have that tool so that things can be recorded and shared. But I suppose initially, the employee has to feel safe to be able to share that information in the first place. So yeah, I think, say safe spaces is really key.

**Steven** That brings us to the end of today's podcast. I want to say thank you to Jenny.

**Jenny** Thank you, Steven.

**Steven** Thank you Jilly.

**Jilly** Thanks, Steven.

**Steven** And thank you, Rosie.

**Rosie** Thanks Steven.

**Steven** For more information about infertility, miscarriage and baby loss and how to support colleagues, visit our website. There's also plenty of signposts in our resources to organisations that can offer your colleagues additional support.

We are now having a little break than our podcasts over the summer months and we'll be back in September cheering National Inclusion Week, with a special podcast with our National Inclusion Week sponsor, McDonald's. Thanks for listening.

**Closing credits** You've been listening to talking inclusion with Steven Copsey. If you've enjoyed listening to this podcast, then please subscribe and leave a review from wherever you get your podcasts