EP Cleft

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Subscribe [00:01:00] to the podcast, download the Parent Sense app, and catch Meg here Every week to make the most of that first year of your little one's life and now meet your host. Welcome back moms and dads. This is sense by Meg Faure, and I'm your host Meg Faure. And I'm absolutely delighted as always to have you with me.

And today we have got a very special guest, somebody who many of you will know very well. And the reason you'll know her very well is that we have tracked her journey with her first. Born Max over the course of many, many months. So if you had listened to that, you will remember Cassidy. And if you haven't listened to her journey and you have got a little one dip into the podcast we did with her, because we tracked Cass and Max every single week for the whole first year of Max's life.

And so you'll be able to go in and actually find out what's going on for a typical 17 week old or typical 24 week old. Max was pretty textbook, although he was, I mean, he was, he is an exceptional little boy. We were biased, but he is exceptional, but he [00:02:00] was, he was a lot of what he went through in the first year.

We'll resonate with all of you. And of course, Cass, like many of us went on then to decide to have a second one. And I'm sure many of you have. Probably even heard, we spoke about that, I think once about, you know, when's the right time to have a second one and Cass went and had a second one. And so we're going to be talking a little bit about her journey today.

It is a very interesting journey. It is not a typical journey. So where Max did things by the textbook, little Zach is not the same. And we're going to be talking all about that today. So Cass, thank you so much for joining us here today. I know. It seems strange to be back. It's like no time's gone at all.

And yet so much has changed. And we were so disciplined in that first year of Max's life. We never missed a single week. And if either of us did have something on, we'd make sure we'd schedule it early in the next week and then do a second one. And I'm really grateful to you. And many moms actually tell me when I chat to them that they follow Cass and Max's journey.

So it's [00:03:00] had real meaning for a lot of people. Well, I have to say I've been quite grateful for it because I've listened to it back and been like, Oh, okay, I'll do that. Or thought, Oh, okay, Zach's not as bad as I thought. You look back with rose tinted glasses and it's quite nice to be able to listen back to Max's journey and first year and think, Oh no, it wasn't, you weren't as good as we remember at sleeping or whatever it might be.

It is amazing. And maybe that's why we go on and have our second and third babies, because we forget all of the stuff that really was hard. And there were moments that were hard in that first year of life. Yeah. Oh my goodness. I have said to Alex a few times, Max never was like that. Zach is so much worse.

And then I listened to the podcast and I'm like, Oh my God, Max was a lot worse. And I found it, you know, that it really is funny how, even though they're two completely different babies and, you know, obviously there are, there are differences. On lots of levels, but actually there are a lot of similarities in terms of the progress, the different milestones that they reach, the challenges that they face, [00:04:00] the, you know, developmental stages and that sort of thing.

There is that, that continuity across both of them for sure. Absolutely. And of course there would always have been massive differences between them because they've got very different sensory personalities. So I'm sure in one of our. Zach, we can explore that a little bit cause he is very different to Max.

So I mean, Cass, I've been along with you for a little bit of this journey, not as much, not as immersed as Max. And I can very well recall around about halfway through your pregnancy where you gave me a call and explained that things were not turning out as planned, and that's what we're going to be talking about today.

So moms. The introduction to today is that little Zach, it has a very severe cleft lip and cleft palate. And that journey for Cass has been quite something and she's still on the journey and will be for a while still. Probably for most of his childhood where he has all need to be having surgeries, but Cass, I would like to go all the way back to the very start of your pregnancy and the start of your journey with [00:05:00] Zach as a, as a kind of a special needs little one in some respects, because they are going to be special needs.

Yeah. So exactly that it sort of starts at the 20 week scan for, I think most parents as well. So and the interesting that we talk about that you know, the regularity that parents go through with, with all the things with cleft parents as well, the journey actually doesn't matter really what type of cleft they have that journey, particularly at diagnosis is very, very similar because it's, I think we all go into our 20 week scan.

Well, I certainly do. And a lot of people I know and have spoken to, you go into a 20 week scan thinking everything's just going to be okay. You know, you know, in the back of your mind that there's a chance that something may not be in your, it's the, they call it the anomaly scan here to check for these anomalies.

But I think, you know, you never think it's going to happen to you. So we went for the scan and actually for us, it was, it was, Quite a [00:06:00] tricky situation because they couldn't get a clear picture of Zach's mouth. So she'd done the whole thing and she kept coming back saying, Oh, I wish he'd just move his hand to see his mouth.

And she was really focusing. But even then, you know, you're just thinking, Oh, come on, Zach, move your hand. And so then they, she said, Look, I think I can see. A cleft lip, but I cannot be sure because his hands in the way, we don't have a clear view. Can you come back in a couple of hours and we'll see if he's moved and we'll try again to get a clearer view.

But you, immediately in that moment, you know that they wouldn't say it unless they were pretty sure. And. For me, certainly, I didn't really know anything about cleft. I didn't know what that meant. I didn't know all I was really hearing is that something's not quite right. Something is different. And the sort of journey after that, it was confirmed that afternoon we saw the consultant who all they could really tell us at that stage was that it was.

a cleft lip[00:07:00] and potentially palate, but actually in utero, there is no way of them knowing for sure whether the palate is affected. And really, you know, I will be quite harshly honest in, in my story because I think it's really Important. If anybody ever gets any form of diagnosis, there are thoughts that you feel incredibly guilty about, and it's quite important to know that other parents are having all of those thoughts.

We did have the discussion bearing in mind. We knew nothing about craft. We did have the discussion on the way home. Do we still want to have this baby? You know, is this we've got Max to think about what are the challenges going to be? We had no concept of what this meant. We had been explained that. I might want to consider having an amniocentesis, which for anyone that doesn't know, is basically a test to confirm whether there are other chromosomal issues in the pregnancy.

It does have a risk of miscarriage to it. It's a very, very small [00:08:00] risk, but nonetheless, it's a risk. And it basically means a very large needle going into the uterus and taking fluid, amniotic fluid, and then they will test that fluid. So they kind of said to us it was completely my decision, but to go back and have that.

So on the journey back, I just remember feeling completely. overwhelmed, emotional, but equally it hadn't really sunk in. So you're, it's sort of a very strange practical view as well. And then we talked about it a lot and it was, I have to say, I think that deciding whether to have the amnio was. One of the hardest parts of the pregnancy.

I think I saw you just after we'd made the decision to have it. And we were waiting to get the date for the amnio. I think I was actually at your house when the hospital called me. And, but it was a, it was a really difficult decision because it is against every logical bone in your body to do anything that puts your baby at [00:09:00] risk.

You know, you're, you're, you're making a choice. Do I do this when there is a chance my baby might not survive? And. Everything tells you don't take any risk, but for us, the major factor was max. We had to consider if there were severe chromosomal issues that were linked to the cleft, then we had to consider the impact that that may have on on our lives, but predominantly on Max's life.

So eventually I have done a lot of research and all the data analysis, which is my my go to we decided it was the way forward. And that was that was quite an emotional decision, but absolutely the right decision for us, not the right decision for everyone. I see a lot of cleft parents really agonizing over that decision.

It is, I think something like a 0. 1 percent chance of miscarriage, but to know that there's any chance for most parents. As I say, horrible. Anyway, we had the amnio. All the results came back completely positive. So then we are in a situation where we know that it's just the cleft.[00:10:00] But of course we have no idea what that means.

And then you have 20 weeks really of waiting to find out how severe is it going to be because they can't really give you too much. Information in the neutral. Obviously, we didn't know if the palette was involved. The lip is it impacts on a very aesthetic level. The palette has more developmental issues with it.

But the awful thing was for us, we almost felt more upset by the lip than the palette at the time because we didn't understand what the you sort of think. Well, yeah, we can overcome. Developmental things. We've got it. We could. I can put a strategy in place for that. But we really struggled with the idea of our baby coming out, not looking as we imagined our baby to look on.

And I remember so many parents. There's a fantastic charity called CLAPA in the UK, [00:11:00] C L A P A which is a charity provides amazing support for cleft parents and children. And they have a Facebook community and I remember all of these parents saying them, right, you know, you get the diagnosis and you think, oh my goodness, I'm not going to love this child the same or.

I don't want, I don't love the way my child's going to look and my child's not going to be perfect and all these worries about that. And then they'll say, but as soon as your baby's born, that all goes out the window. And Alex and I sort of quietly, I remember one evening. I'd both quietly admitted to each other, sort of feeling very guilty about our thoughts, but we just said.

I just don't think that's going to be asked. I'm not, I'm not going to love this baby in the same way that we love Max's perfection. And this is baby. Isn't going to look the same. And is it going to be quite a sort of ugly babe? And you sort of have these thoughts. We had these thoughts and we thought we're really, then you are suddenly thinking, Oh my gosh, I'm this person.

I didn't know. I [00:12:00] was, I'm shallow and I'm, you know, got characteristics that I really don't like it myself that I'm finding out about. And we really did believe, you know, we're just not like all these parents, maybe we're awful people, but we're just not going to feel that we're always going to see the cleft.

We're always going to see it. We can't wait for that first surgery when they deal with the cleft and it's gone. We just want that time to come. And we, we are obviously not as good people as the rest of these people, but that's how we feel. We can't help it. And we went through. Pretty much the whole pregnancy sort of the rest of the pregnancy for saying, are you feeling any better about it?

And I think sometimes we would say we were, but we were probably just trying to tell ourselves that we were, whether really in the back of our mind, we thought, no, this is, you know, and, and then of course there's a huge amount of anger that we felt as well. Why us you know, why, why does this have to happen to our baby and to our family?

And. you know, initially you, you don't have a [00:13:00] baby there. So you're thinking about you and your baby that is there rather than the impact it's going to have on Zach. Yeah, absolutely. Yeah. So Cass, I mean, I want you to pause there before you get onto little Zach. being born because obviously there's just some incredible parts to that journey and, and you can tell us whether or not you did fall in love with him.

But I first want to just go back to the stage of pregnancy and I can remember very clearly you were actually at my home and you got the phone call from the hospital and you know, you were really tossing up some very hard decisions at the time because you know, aside from the risk of losing.

Zach, there was also the risk that the results could come back negatively and, and then you'd have to face some very, even maybe even more tough decisions. I was sitting across from you and I was looking at you as I am now. And I was very burdened for what would come out of my mouth and what I could say.

And I think a lot of moms who listening may not necessarily themselves be, have a cleft [00:14:00] baby. And we know that I, I think you told me it was at one in 700, one in 700 are born with a cleft. So that's actually in the UK, three cleft babies a day. Okay. Which is not an insignificant number. I mean, it's more than people realize.

But you and I did a survey yesterday on my Instagram page to find out how many moms had been touched by clefts. And so either had a baby with a cleft themselves or knew of somebody who did. And the unbelievable number was

30%. So one in three parents on the parents page on the make for a page. In fact, it was have been touched by a family who have a cleft baby.

And so they have definitely set like I did and looked. at their friends and wondered what is the right thing and wrong thing to say. And I wonder if you could help us there a little bit, just give us some guidelines of the things that are really not helpful to say or to hear and the things that really do, you know, what, how people who don't have cleft babies can respond.[00:15:00]

I think it's a really interesting one because at the time. I didn't even know what the right thing to say or do was. So even, I mean, even now you, I suppose there's, there's, I think the trouble is, is everybody's different to what they're gonna react to and what they're not going to react to. And I think.

I was having quite harsh thoughts myself, so probably could have dealt with some harsher comments myself, because if anything, it may have given me comfort that I wasn't an awful person. But I know a lot of mums and dads of cleft babies are really do struggle. I think the struggle comes more when the baby is born and people's reaction.

To the baby itself. One of the things that I would say that really helped me or was really touching was when people asked questions and wanted to know more, you know, asked where can I find out more? Because [00:16:00] I think that that made me really feel like those people cared. Yeah, I think we, we often live in a world where we're too scared to ask more questions, or maybe it's that we don't want to look ignorant, or maybe it's that we don't want to ask to pry.

But I remember friends sort of saying to me. Sorry, I don't really know what, what does that mean? Can you give me any information? And I would send them the clapper website and say, you know, just read this. This has got everything you need to know to understand. And maybe it's worth, if people do what we can put the website in the show notes or whatever it's called for this, because they'll explain things far better than I ever can.

But I think that was, that's the thing is. The not, not worrying about looking ignorant because I didn't know any, I didn't know what a cleft meant. I didn't know how severe it was. I didn't know what impact that would have on a baby. You know, and I think, I think that's the other thing that some [00:17:00] people said, which I did find unhelpful.

And I know that they were just trying to be really kind. Was they'd say things like, but he'll have the surgeries and then it will all be fine. And I really felt like that was belittling what we were about to go through. It was sort of a, you know, it could be a lot worse. He'll just, and of course it could have been so much worse.

And I was very aware of that, but we still had a very, on a practical level. Yes, Zach will have surgeries. And as an adult. He will be absolutely fine. There are plenty of examples of people who, you know, in, in the, the celebrity world who have had, were born with a cleft and are absolutely fine. I think Hakuin Phoenix.

I know I was just funny enough. I was watching the trailer of Napoleon last night and he's Napoleon and oh my gosh, he is. Just so hot husband. I said, I think he had a calf. So and we do know having met Zach, well, I actually don't want to take away all the thunder because we'll talk about how gorgeous Zach is just now, but I agree [00:18:00] with you, you know, it's certainly, you know, it, it, it is something that long term doesn't have to, you know, aesthetic.

Absolutely. But I think the, it's not helpful to hear that practical level it is, but yeah, because there's actually. There, it's still a hugely emotional journey for Mm-Hmm. And I, you know, as we say was I can talk a bit about what the actual reality of having a cleft baby is. Yeah. But also in that moment for that parent who's had that diagnosis, it's huge.

Mm-Hmm. You know, it's. It's everything, the thoughts, you know, you, you go to have your second baby and you imagine what it's going to be like. This episode is brought to us by Parent Sense, the all in one baby and parenting app that help you make the most of your baby's first year. Don't you wish someone would just tell you everything you need to know about caring for your baby?

When to feed them. How to wean them, and why they won't sleep. Parent Sense app is like having a baby expert on [00:19:00] your phone guiding you to parent with confidence. Get a flexible routine, daily tips, and advice personalized for you and your little one. Download ParentSense app now from your app store and take the guesswork out of parenting.

First of all you think, I kind of know what I'm doing this time round. You've got images of the two brothers, you know, playing together and, you know, it all being quite easy. And we, you know, in our eyes, we were very lucky. We've got a nanny. And so I was going to, you know, leave her with these two boys and they were going to be the best of friends.

And I was going to go off to work and it was just going to, we were going to have this lovely family. And you know, every, the, the, The bow in the bundle of the, the image, you know, was, was a certain way. And we had a certain vision and everything was, you know, Zach Ward's going to take the same path that Max took.

And then suddenly that's not going to happen. And because you don't understand it, you start to catastrophize things, you know, in your head and you read things. And, you know, in [00:20:00] my mind, I thought, Oh my God, I'm. not going to be able to leave him. So I'm not going to be able to work. So we're not going to be able to afford this house that we're living in.

So, you know, what we actually, we've just moved into this house. What do we need? And suddenly having had a cleft I'm thinking we need to move into a smaller house that like, cause my mind had gone in this direction. So. There are a lot of ripple effects of these sorts of things that do become huge in a parent's life and, and the impact seems huge.

So in that moment, when you're saying, and they're trying to be reassuring saying that he'll have the surgeries and everything will be fine. Well, a, we don't know that because we don't know how severe it is. So, you know, and B, there are. Other impacts. He might have to be tube fed. He might have hearing loss.

He might have he might not be able to speak properly. He, you know, there are lots of other impacts that a cleft can have on children. In most cases, the, you know, if there are any speech challenges, they are up [00:21:00] to a average speaking level by the age of five, certainly by the age of the time they're going to school with hearing, they usually grow out of any hearing challenges at six or seven.

And do those hearing losses, if they are hearing losses, can those get diagnosed quite early? Yeah. So the amazing thing is as soon as you are diagnosed, this is in the UK, so I must just caveat this is the UK. I don't know how it works anywhere else. But in the UK, as soon as you are diagnosed, you are assigned a cleft team.

Now for us, we are obviously in Jersey. So that cleft team is in London. But it's your closest cleft team or the most convenient cleft team. And in that team you are assigned a cleft nurse. A surgeon, an audiologist, a speech and language therapist, a psychologist, an orthodontist, and I think also a dentist is in that team as well.

That is your child's cleft team. And aside from maybe retiring or moving on, those [00:22:00] people will look after you, your family throughout the whole journey. Remarkable. The majority of the journey is from what I understand, kind of the final surgery, I should caveat the final definite surgery is between 7 and 11 years old.

There may be additional surgeries required, but there are certain set surgeries that occur. And. Then, you know, but, but that support from, for example, psychologists in the teenage years, if Zach looks different or something that, you know, it will impact the way he looks as a teenager, that can be quite difficult to, you know, kids, kids can be cruel at the best of times.

Yeah. So you do catastrophize what could happen in the teenage years. And that's why the psychologist is so amazing, you know, when we're talking about that psychologist will be assigned to Zach and. He will have, in this case, it's a her I think. He will have her to talk to, [00:23:00] write up through those teenage years.

So it, you know, it's a practically, it might be the surgeries are done, but there's an emotional side to it for Yeah. Yeah. So quite remarkable that you have this whole team. Now, I know that one of the questions in the second half of your pregnancy was, how severe is this going to be? And there is definitely a scale when we start to talk about clefts from very minor cleft.

Lips all the way through to the more severe soft and hard palates. Could you talk through that range and then use that as a segue to go into how, how you established what, where he was just after birth? Yeah. So. There's, there's either unilateral or bilateral cleft lip, so, and palate, but, so a unilateral basically means it affects one side, bilateral means it affects both sides.

Zach was diagnosed So that would be a gap between running down from the nostril, down towards the lip on both sides. So it's actually, yes, but it's actually the other way around because it's from the lip [00:24:00] up because, and the reason I say that is because you can have an incomplete or a complete. So an incomplete doesn't go all the way up to the nostril.

A complete will go all the way up. So, zach is complete. He's we knew this during pregnancy. We knew that he was going to have a complete bilateral cleft lip, which aesthetically is the furthest lung that you can could know about at that stage. That's as far as we could know in terms of his palate.

He has. No roof to his mouth, but we obviously during pregnancy, they said they really did feel that the palate was going to be impacted, but they could not tell us for sure. So we were kind of warned that it was a possibility and probably quite likely, but we didn't know for sure whether it was going to be impacted.

And that's really difficult as well, you know, that you can't know about palate because you. Then don't know. Well, okay, is it just going to be, he has his lip fixed [00:25:00] in a surgery and then that really is the end of it really because there's no internal impact? Or are we looking at, we have these longer term issues?

Mm-Hmm, . The other, the, I mentioned a surgery between seven and 11. That is. To do with the gum, it's an orthodontic piece, basically, I didn't know this, but adult teeth has to grow through bone when it comes through. And obviously because if they have a complete cleft across the gum, there is no bone.

there. So they need to do a bone graft before the adult teeth come in where they take bone from the child's hip and then complete the jaw so that the teeth can grow through. Cass, it really is quite an all encompassing condition. This it's hard. So take us through, so take us through now the moment that he's born because obviously this is a high risk birth because they don't know what they don't know.

I don't think there [00:26:00] was a medical professional in Jersey that didn't know about Cassidy and her cleft baby. And actually that's another thing because we live in such a small place. I happen to know that the lady. Who did Pilates after me was a pediatrician. And I remember being so emotional after we got there and so panicked and just not understanding.

And I went to Pilates and she was going in after me and I am so embarrassed, but I completely accosted her. And I said, you don't know me. My baby's just being diagnosed. What does, and she was. Yeah. You have to talk to a doctor, not me now. And I was just, you know, because I just thought, Oh my God, please someone give me something, please.

Someone give me some information and tell me it's going to be okay. So I'm very sorry to that. If she's listening, I'm very sorry. But. Yes. So, so everybody knew we were on Red Alert and the, the major difference really for, Oh, well, so [00:27:00] there were other having had, I don't know if anyone remembers, but I had probably the easiest pregnancy I could have ever wished for with Max.

There were multiple other things that occurred during my pregnancy with Zach. I had hypothyroidism at 37 weeks. I was also diagnosed with gestational diabetes, which was a real shock. And I'd had hyperemesis in the first trimester, which actually also led me to be quite well, because they say part of one of the, one of the many reasons that you potentially may have a cleft baby is if you haven't had enough folic acid in the early stages of your pregnancy.

And I wasn't able to keep anything down at all. So I had this concern of, was it that I had been taking the supplements, but nothing had stayed in. I was assured that that was probably not the case. It does just happen. Randomly. So, but so I'd had hyperemesis in the first trimester, then we got the diagnosis, then I had the amnio, then I got hyperthyroidism, then I got gestational diabetes.

So, but so [00:28:00] because of the gestational diabetes, they, we had been considering. I'd been asked to consider a C section for the birth which I really didn't want to. I really loved childbirth with Max. Anyway, I was lucky enough that the gestational diabetes wasn't severe enough and I was able to have a natural birth, but they were going to have, I wouldn't, wouldn't be able to go too far over term.

However, luckily for Zach, I was at my client's office on the Friday, said goodbye to everyone, said I probably won't come in next week because I'm 39 weeks next week. And luckily I didn't because on the Monday at four 30 in the morning I went into neighbor, my waters broke which I had again, hadn't had the experience of my waters breaking with Max.

I'd been in hospital when that had happened. So I was very confused. I didn't know if I'd become incontinent overnight or if I had actually, my waters had broken, but because of the cleft, I had to go straight into hospital. There was no sort of waiting to get to second stage or anything like that, because it was vital that I was [00:29:00] in hospital for Zach when he was born.

Because obviously they needed to take him straight into neonatal. So we, we rushed off to hospital, I won't go into too much detail about the birth, but it was super speedy. He, in fact, the doctors checked me, I think at nine o'clock and he said, we'll come back in four hours to see how you're doing.

Cause I was only three centimeters, two hours later, Zach was with us in the world. And I'd said to the midwife, I think he's coming. No, I don't think so. Let's just have a look. And I was like, no, I have to push now. And I actually, I was very lucky. I had my trousers down to be honest. It was that close.

So, but because of that, that does need, so Zach. Actually when he was born, he wasn't responding. He was quite blue. He did cry initially when he was born, but once he was then sort of breathing and lying down, his tongue kept flopping backwards and causing problems. So he was immediately taken from [00:30:00] me.

The buzzer was sound. Did you see him? I was holding him. And what was your immediate response to him? Did you, did you have the rash of oxytocin and the falling in love? Or did you, was it like, Oh my gosh, this is a shock. This is, it wasn't a shock. So we had done again, this is something that's offered in the UK.

You can go for a 4d scan that's paid for by the charity clapper. And the, the benefit of the 4d or 3d 4d is video 3d obviously is 3d. You can see your baby in 3D form in utero now, of course, it doesn't give you an exact picture, but you get a much clearer idea of what to expect when the baby's born.

And they do recommend it here for cleft parents so that they, that initial shock maybe isn't there. And we were there for a bit more prepared. There are parents who have no idea until birth that their baby's going to have a cleft. So, you know, that, that would be a huge shock. So [00:31:00] it was, as I had expected it to look, I'd looked at enough pictures of other children.

Also he was so tiny that actually, therefore at that time, the cleft is very tiny, but to be honest, it was so quick. I remember thinking to myself, okay, it's as you expected. And what I do remember thinking is. Cause there'd been a bit of hope in me that it wouldn't be as bad and I remember just saying to myself, okay, it is, it is as bad as we thought it was going to be.

That, that hope was in that moment gone. But no sort of, Oh God, that. I had just given birth. I was a bit delirious and they sounded the buzzer for Zach very quickly and also had to sound the buzzer for me because due to the speed of the birth, I actually started losing. I lost quite a bit of blood quite suddenly.

So my poor husband was standing between my bed and then they had the neonatal team that had been rushed in. And had the oxygen mask on [00:32:00] Zach and were holding his head and trying to hold his tongue and trying to hold it, hold his head in a position that stopped his tongue falling back. How did that stop?

Cause he, I mean, he hasn't had any other apnea episodes. So how did it, does he just learn to keep his tongue forward? It's just strength. It's just, yeah, he's just so floppy when he's fat and doesn't, has never had to do it. And it was a short period of time because they actually had. The equipment ready to put him on a breathing support.

And by the time they got him to neonatal, they didn't have to do that. But they, they had all the strapping around his bed and everything too, cause they thought they were going to be strapping him up. So yes, my poor husband, Zach's on one side with a team around him. And then the next thing I'm on the other side with a team around me, they're putting drips into me and.

you know, doctors coming in and everything. And Alex is just standing there going, Oh my God, which way do I go? And he said, he, he just had a moment where he thought Cass is going to be furious with me. If I don't listen to what they're saying about Zach, she's going to ask me so many questions and I [00:33:00] need to know the answers.

So he, he gravitated to go towards that. So yeah, the birth was itself and then. Everything calmed down, but by the time I didn't have a team around me, Zach had been taken. He was in neonatal by then. So they sort of said, when do you want to go and see him? I said, now. I want to go now. And so we went through and I think.

It wasn't so much that it was a shock and I wouldn't say that I was in love immediately at all, but then interestingly, I don't know if I felt that with Max either. I don't know if I had this again. Max was taken from me for, for, I don't know if people remember, but he was taken here. It was born with an infection.

So he was taken from us quite quickly. So we didn't have that bonding time with him. Yeah. And so I think that's quite key that possibly that oxytocin and falling in love happens while you're holding your baby skin to skin in that moment, you know, I mean, and I'm just sorry to interrupt you there, Cas, but, you know, I think that, and [00:34:00] we've, we've actually done episodes on this, that bonding is such a variable thing.

And you can have a baby who is on your chest with you you know, no, no, you know, kind of left lip or left pallet and, and be not fall in love at all. And it can take months and you know, and I think that's one thing that parents all need to hear. You know, there's this romanticized view of as your baby hits your chest, you're going to fall in love.

And it does happen. It certainly does happen, but for some parents it just doesn't. And it takes a long time regardless of what the baby looks like and regardless of whether or not they're with you. So and I think it's important to normalize that as well because people don't all fall in love instantly.

It's, it's kind of this expectation. And I think a lot of people find their babies. quite ugly on the day that they're born. And it takes a few days to kind of fall in love and go, Oh my goodness, this baby is so beautiful. And I love it. Oh my goodness. Max looked like Winston Churchill. I mean, it was, you know, and, and I think it's absolutely true.

I think I had always tried to find an excuse as to why I didn't feel that. And I told myself it was because they were taken away. The, the [00:35:00] reality is I just didn't feel, I just didn't feel that. And I would be interested. I think it's a poll that I must definitely do is to know how many parents actually do feel it on the day of the baby's born and for others, how long did it take?

Was it a week or three weeks or was it actually six, seven months, which also does happen? Certainly. I remember a friend who had a baby not long after Zach and she messaged me saying, my goodness, I just love him. So I can't, I can't love anything more. And, you know, really sort of just. Telling me how much she adored her baby.

And I remember thinking, do you really, or do you think, because I'm not feeling that, is that, that you really feel that? Or do you think that's what you should be saying? I don't know. And you see parents who listening to this, like I'm, I'm a parent is listening to this and mine, mine are kind of, you know, in close to their twenties or, you know, my youngest and she's, she's 18 and.

Of course, in my head, I'm thinking I fell in love instantly, but the truth is just like we spoke about right at the beginning of this episode is that you've actually forgotten you know, and I think that often happens is that people look back and they go, Oh, I'm sure there was instant love, [00:36:00] although I must say with him, with my third.

I don't think it happened like that because, I mean, I had had a cesarean section, I was in a huge amount of pain I had two toddlers who were all over me and, you know, creating more pain. So yeah, I, I don't know that necessarily I did fall in love instantly, but yeah. Yeah. And I think the other thing with Zach is that there were so many practical things to get through.

Yeah. That, I think that also was some boxes that you had to tick. There wasn't, yeah. There wasn't a honeymoon period for, for us with Zach. Mm-Hmm. Absolutely. There I have some lovely pictures of me holding him and I remember thinking, I'm gonna do everything in my power to protect you and to make this all okay.

But I didn't I didn't think. Yeah, the emotional side wasn't there. So we had a few hurdles that he had to get through before he could leave hospital as well. So he had to pass some tests. He had to be able to sit in a car seat. He was all hooked up to monitors and that sort of thing. But of course the big one was [00:37:00] feeding for, for Zach.

Was he going to be able to feed? We knew, and another hugely difficult thing for me. During pregnancy was, I knew I wasn't gonna be able to breastfeed him. That wasn't gonna be an option. And I'd breastfed max. I'd loved breastfeeding. I think I actually talked, got quite emotional when we were talking about me finishing breastfeeding with Max on, on the podcast.

And, but I knew I was, there was no chance of me breastfeeding Mac Zach at all. And that was really hard for me. Yeah. To come to terms with. The next stage was where we even going to be able to bottle feed him, or was it going to have to be tubes because cleft babies sometimes have to be tube fed.

They can't have a bottle because there's no palate. They can't suck. So that's why the, the bottle sometimes. Have a challenge, although he is on specialist bottles. We lucky he was able to feed. He didn't have to go onto tubes. They tested him. It was the most ridiculous situation I've ever had for the [00:38:00] first 24 hours.

Of course, that decided to come on a bank holiday. So his cleft team were not contactable the day he was born and the team in Jersey weren't experienced enough to try oral feeding. They said, you know, they just, and they did speak to somebody at the cleft team and they said, don't. do any oral feeding until, you know, the team are back.

So he was on tubes for 24 hours. And then I had to give him a bottle on his, on day two. And I had the Jersey speech and language therapist who also she specializes for the feeding, the Jersey breastfeeding specialist, the neonatal nurse and then on video conference, Mike, the cleft nurse. Wow. All of these people around for us.

Nothing like a bit of pressure. First bottle feed. But he took it amazingly and he's been on bottles ever since and he is a chunky, chunky monkey. He likes his food. So we were really lucky on that level. I don't know how. [00:39:00] I was really worried about the tube feeding because obviously then you've got to learn a whole new skill.

And if they pull out the tube, you've got to go back into hospital regularly for them to put the tube back in. It adds a whole other level. I don't really know what differentiates them between whether they can or can't, why some can, why some can't. I've never really understood that. Because as I say, Zach.

Literally has no roof to his mouth when he opens his mouth, you can see a septum and that's all that's up top though. You know, we, we were very lucky. Yeah. Cass, what an unbelievable story taking you through until the day he was born. I want to read a message that you wrote on the day that he was born and this is your very first message said after he was born.

So we had all wished you congratulations. And you said, thank you all. Zach is beyond gorgeous. Well, your first words about him, I'm awaiting the video consult with his specialist in London tomorrow to know if they're happy for him to try oral feeding rather than tubes. But other than that, he's doing well, feisty, strong, and fidgety have so far been the words that have been used to describe [00:40:00] him by the nurses.

And of course that is him. I do want to add for everybody, cause I have obviously seen and held him. That he is utterly gorgeous. I mean, there is just no other way to describe him. He is a very, very good looking boy. And I think, you know, I mean, when you just see past it, I don't know that you even see the cleft when, when you get to know him.

And so he really is a gorgeous boy, but of course that doesn't take away from the fact that this is a massive journey. And I think, unfortunately we don't have more time, although I think we must definitely do another Conversation about this because there are people who are going to want to know more.

But you did mention to me when we came on today that he has got his first date for his first surgery. And when is that? Yeah. So this morning we got the call. It's on the 15th of February. So that's a month away from today. So, and I think, I think it would be. There have been a lot of challenges that have come in those first few months.

And I think you and I have discussed that some of those are actually relevant, whether you have a cleft or not [00:41:00] you know, Zach, for example, he can't suck. But what that means is he can't self soothe with a dummy, but it, you know, so we've had to find alternative ways to help him soothe the first few months were very challenging because his only comfort was being on.

So he was on me all the time and that was really tough. But, and, and the next sort of, sort of just while we're talking about that cleft journey and the emotional side of it, what I do know is that we have a very. Having during antenatally thinking we couldn't wait for this first surgery. And I'm already going to get emotional.

I wish I could just hit pause now. Once that surgery happens, the little boy that we have fallen in love with, we'll never be there again. His face, he will be there of course, but we will never see this face again. And that's our baby. So, yeah. Yeah. I mean, that's really huge Cass. I mean, he is. He is going to look very different [00:42:00] and we are, we've all just fallen in love with who he is right now.

Of course, his feisty character and who he is inside. And we'll talk about his social, his personality, but he is a social butterfly that will all be there. Absolutely. And he's got a huge, huge smile. One of the best things about cleft babies is how big their smile is because there's no limit. Their mouth doesn't, it's not joint, takes over his face.

He really is. He's actually gorgeous. And we, we just adore him, but his eyes really smile when he smiles and that will still stay the same. So that's, that's wonderful. Yeah. Oh, Cass, what an incredible journey you've got ahead of you. And thank you so much for sharing. You have the most amazing way of making.

Things that, you know are really hard you know, kind of talking about them and sharing them. And, and we do really appreciate that. I know that there'll be lots of parents, both of cleft babies and those who've been touched by families with cleft babies who will really have appreciated this. So thank you for sharing today.

No, that's a pleasure. And I think you know, it's the case with any diagnosis. Maybe if you, when you go for that 20 [00:43:00] week scan, if your baby isn't going to look how you initially imagined, it doesn't just have to be a cleft. It, it, there are all sorts of thoughts that you, I think I really want to stress.

You're not a bad person for having because probably every single person is having them. We maybe don't want to admit them, but we're all having because it's completely natural. And I think we gave ourselves a really hard time that we were actually, thank goodness we had each other both having the same thoughts, but we gave ourselves a really hard time.

So, you know, don't do that if you, if you are having those thoughts. Yeah. Well, I know I said this to you at the time when I was trying to find the words, which I really found very difficult when you were, when this, when this, the, you got the diagnosis early on is that Zach chose the right parents and that is absolutely a fact.

I mean, you and, and Alex are just remarkable the way that you handle things and your candor telling each other that you know, I don't know if I'm going to fall in love with this baby with how he looks. where it feels so shallow and being able to actually say that to each other. Yeah. We're very lucky.

Yeah. You are. And I remember [00:44:00] we, we, that's how we felt eventually in the pregnancy, we actually saw it as a huge compliment that, you know, whatever, however the universe works, the fact that we had been chosen to be the parents actually meant that. It was a huge compliment to us as, as people that, that Zach had decided we were the people who, who were going to look after him and help him through this journey, and it was, it was a huge compliment.

Of course. And I think you guys are the blessing in his life. And I think equally, he is going to be a massive place and he is already a massive placing in your lives. Absolutely. Cass, thank you so much for today. I do appreciate it. And we will definitely catch up again. Definitely. Thanks so much, Meg.

Thank you. Bye. Thanks to everyone who joined us. We will see you the same time next week until then download parent sensor and take the guesswork out of parenting.