**Navigating Cleft Lip and Palate: Surgeries, Challenges, and Resilience S5|129**

In this 129th episode of Sense by Meg Fora, we are revisiting our journey with Cassidy. You will remember Cass from season one. We tracked her little one Max.

Amazing, amazing journey all the way through his first year of life. And here I'm going to give you a couple of snippets of the questions that I asked her today. So Cass, when we last chatted, you had literally just got the date for Zach's first operation and he's now had two surgeries since.

Fill us in, tell us what the year in Zach's life has been like. He looks so different. The first surgery was a very dramatic change in the way that he looked.

But I look at him now and... Weren't you scared that he was going to wake up and you wouldn't be there? I was never going to go very far away. And actually they call you when he's still in recovery. So if for any reason he had woken up before, he's still in recovery, he's still coming around.

As long as you're not going to go too far away, you'll be back. Did you grieve his new baby face, the original face, or did it just evolve and you were fine? Initially, it is difficult because you go from... What sort of things do you think could be learned from your experience, having gone through it twice, that just would make things a little easier for parents? Welcome to Sense by Meg Fora, the podcast that's brought to you by ParentSense, the app that takes guesswork out of parenting. If you're a new parent, then you are in good company.

Your host Meg Fora is a well-known OT, infant specialist, and the author of eight parenting books. Each week, we're going to spend time with new mums and dads, just like you, to chat about the week's wins, the challenges, and the questions of the moment. Subscribe to the podcast, download the ParentSense 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, mums and dads, to Sense by Meg Fora. I'm Meg Fora, and I'm your host here today, and we're going to be talking about all things parenting, all things baby.

So each week, we are joined by a guest, and sometimes the guest is an expert who focuses in on a subject matter like weaning, or feeding, or allergies, or fertility. We've had all sorts of amazing guests in this season. And sometimes it's a fellow mum.

And of course, our mums are very often quite expert themselves on their babies. And the mum that you've heard the most from on our podcast is Cassidy. We followed Cassidy's journey all the way through from the birth of Max, literally within a couple of days of him being born.

We followed him through his first year of life and into his toddler years. And then earlier on this year, we met up with Cass again. It was episode 93, for any of you who want to go back and actually have a listen, where Cass introduced us to her second baby's journey.

And that was the journey of Zach. And Zach had had a much more complicated journey than Max, because he was born with a cleft lip and a cleft palate, which is quite complicated. And so they've gone down the road of surgeries and hospitalizations, and in the early days, acceptance, and going forward after the surgeries, just dealing with all of the kind of aftermath of hospitalization and so on.

But it's a very, very positive story. And after we spoke to Cass, just when she's chatted a little bit about Zach at the beginning of the year, there was an incredible number of people who reached out to me to thank me for having Cass on and to just really reach out to Cass as well. People have loved her journey, loved tracking Max, who's now two and a half, and now just wanting to hear a little bit of an update on Zach.

So it is a huge and very warm welcome back to you, Cass. Look, introductions make me emotional. It was really quite emotional because you were so, I mean, I said it to somebody recently, you were so incredibly dedicated to documenting Max's journey and his life.

And I remember at the time saying to you that it's such a universal journey that when one baby hits 17 weeks, most other babies are doing a very similar thing. And it is exactly like that. Many of our moms, even now, are following Max's journey so that they can see what their baby should be up to.

And literally this morning, I had a chat to somebody who said that she'd gone on, she'd listened to the four-week-old episode of Max, and she couldn't believe it because her baby was doing exactly the same stuff. So it is such a universal journey. And yeah, we got to know your voice very well.

Yeah. And I have to say I did it the same with Zach. I was going back and listening to Max Oh, it's okay.

Or why aren't you doing that? Your brother was doing that by now. Yes. And of course we actually thought we'd set out to go and document Zach's journey as well.

But I think just the juggle being very real with two and a career, because you are a career woman and having the health issues, we just never got around to it. So I'm really delighted that we're just touching base a little bit on Zach's, you know, development as he goes along. Yeah, definitely.

I mean, it's interesting for me personally, I think the transition from one to two has been far greater than the transition from naught to one. And, you know, that's definitely nothing to do with the fact that Zach was born with the cleft lip and palate. It's just having two is really full on.

No, it is. It definitely is. And particularly, I mean, you do have help because you're a career woman, but, you know, in the UK, there's a lot less help for mums, you know, whereas in South Africa, I found my move from one to two actually wasn't that bad because my move from naught to one, I didn't have a live-in nanny.

I didn't have a nanny. I was very much looking after James on my own and I was in a permanent drown, not knowing what the heck I was doing. But when it came to Alex, I then had a permanent live-in nanny and my husband was around to look after James.

And so for me, the jump from one to two actually wasn't massive, but I found the jump from two to three massive. So warning to you, Cass, if you're thinking about that. No, no.

No warning. He just said that's not happening. So... I've got cut to a year and I'm on the podcast again.

Oops, there's a third on the way. Well, we're here for you if you... Yeah. So Cass, when we last chatted, you had literally just got the date for Zach's first operation and he's now had two surgeries since.

Fill us in. Tell us what the year in Zach's life has been like. Yeah.

I mean, it's crazy because it feels like it was only yesterday, but at the same time, so much has happened. It feels... Yeah. It's very strange, especially now because obviously that transition, especially from the first surgeries, he looks so different.

The first surgery was a very dramatic change in the way that he looked. But I look at him now and if I didn't have photos, I would have forgotten how he looked before. It sort of seems like a distant memory.

And in some ways I do sometimes see photos of him before and feel a bit sort of sad and sort of think, oh, I missed that face. But he looks amazing now. And he, I mean, he is, people do comment, he is the smiliest, happiest baby, which, you know, considering he has gone through two surgeries, you know, he's so amazing that he is just not fussed at all.

Even the nurses in the hospital, they've always been sort of commenting on, my God, less than 24 hours ago, this child was in surgery and now he's completely unaffected. So in that sense, I think it was definitely, when we spoke, I was in a stage where it all felt very daunting. But now, you know, I realise, and people can say it to you a million times, and I think any mum who maybe their child is about to go through surgery will hear me saying this, it doesn't change the way you feel before.

You can hear it a million times, it's still going to be daunting. But it really is okay. And it's over very quickly in the grand scheme of things, because they are so resilient and they get over it so quickly.

But yeah, he had his first surgery in February. And as I say, that was the most dramatic in terms of the physical change that we saw on him. And we definitely learned a lot of lessons from that surgery as well.

So that the second one, or I should say, we learned a lot of from the aftermath of that surgery. So that the second surgery, actually, in comparison, felt like a complete breeze, just because we actually were better prepared mentally, we knew what to do, we could strategise a little bit better. So yeah, that was a big.

So talk us through, I mean, we'll definitely come back to Zach's cleft. But let's talk a little bit more generally about hospitalisations, because that's something that so many parents have to go through in the first year of life, for whatever reason, whether it's something as benign as grommets, or whether it's something a whole lot more serious, like a hole in the heart, so and everything in between. And what sort of things do you think could be learned from your experience having gone through it twice, that just would make things a little easier for parents? Well, I think the first thing I would say, for us is during, and this is also observing other parents that were in the hospital with us as well, my first kind of major tip is if your child is, for example, going into surgery, that leave the hospital during that surgery, I think there can be a real temptation to sit and wait.

But you end up just clock watching, and then you start to feel anxious. And you, you know, what I thought they were going to be done by now, and what's going on? And why is it taking so long? And is there a problem? And why are they not calling? And, you know, that's the thing, whereas we were advised actually, by our cleft team to leave the hospital, go for a walk, go and do something. So, you know, we, we actually went for lunch at a nice restaurant nearby.

And it sounds very, a lot of people might listen to that and think, how could you sit and have a nice lunch while your child's in surgery. But actually, what it meant for us was, we were in a much better headspace when he came out of the surgery, we to kind of be the best we could be for him. And we weren't spending the second surgery, especially, he was in there for five hours.

So it's a really long time to sit and, you know, kind of go where, where is he? What's and they don't know how long it's they can't give you a definite time with any surgery. So I think that's the first kind of major tip is, is remove yourself from the environment. And now to say go for a walk or just do something, but to sit by their bedside waiting for them to come back is it's not, I don't think it's the best way for your, your health, or certainly for my health.

And I, as I said, observed other parents, there was a dad who came in the day, the day after Zach's surgery, he came in with his son who was having a kidney operation, the baby was 11 months old, and he did just sit and he was pacing and he was struggling. He was saying to me, like, I don't know what's taking so long. Why is it taking so long? I haven't heard anything, you know, and that sort of thing.

And I think I sort of kept saying to him, just go out, but they will call you as soon as they they know. So that that would be a definite during the actual thing, top tip. Weren't you scared that he was going to wake up and you wouldn't be there? I was never going to go very far away.

And actually, they call you when he's still in recovery. So even then, we had a vague idea of the time. So actually, we were back both times when we knew it wasn't going to be less than four hours after we took it down.

So we were back by then. But also, I think, if for any reason he had woken up before, he's still in recovery, he's still coming round. As long as you're not going to go too far away, you'll be back before, you know, and there's even when we went down both times, you know, they're still performing checks, they're still doing things.

It's almost, you know, that he was still coming around, he was still unaware. And actually, they said, until I arrived, he wasn't distressed at all. And as soon as I arrived, that was when he became distressed, because suddenly it's, you know, mummy's here.

So, so yeah, I think, you have a vague idea. Don't panic too much if it takes longer. And just remove yourself at least for some of the time from from the environment.

That was definitely my, my biggest tip. And also, I think, for hospitalisation in general, even if they've not gone to surgery, like, ask the staff to show you where's the parent room? How does this work? What so that you can then be a bit self sufficient, because once you're fully, you know, admitted, and in it, you want to be able to do things when you want to be able to do them if your baby needs something or something like that. And I think, again, from observing others or feelings that I had myself, if you don't kind of when you arrive, like, okay, where's the loo? Where's the parents room? How does the fridge? Yeah, where's the fridge? Do you sterilise? Do I sterilise? How does this work? Because then that you find out at the time that it's you need it to happen, and you don't want the delays then.

Maybe it's a sense of, you kind of don't have as much control for other things. So control the things you can. Yeah, exactly.

Absolutely. And did you sleep overnight there in his room? But room Meg, that's definitely wasn't a room. We were on a children's ward with lots of other beds.

A room was a luxury we did not have. But yes, I did. I was there.

The first time I was there two nights, and that was sort of my own request, because I didn't know about the aftercare the second time, I felt much more confident. And so I was only there for one night. In fact, we were discharged by 11 o'clock in the morning the day after his surgery.

So it was after five hours surgery. That's incredible. Yeah.

Yeah. It's all dependent on the fluids that he's taking and so on and so forth. But yeah, I did.

And did you find there was a disruption to his sleep? I know they obviously would have been with things like, you know, pain and so on. But was there a disruption with after the hospitalisation as well? This episode is brought to us by ParentSense, 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? ParentSense app is like having a baby expert on your phone guiding you to parent with confidence.

Get a flexible routine, daily tips and advice personalised for you and your little one. Download ParentSense app now from your app store and take the guesswork out of parenting. But was there a disruption with after the hospitalisation as well? Yeah, I think, to be honest, that's the hardest part of it all.

Always for us anyway. I saw on the Cleft Facebook page, there's a community page for parents. And it seems like it's quite a common thing, not necessarily pain related.

But it's almost like some parents describe it, they feel like their child's a little bit traumatised after a general anaesthetic, they don't like sleeping. So actually, what we did, and it turns out this is what a lot of other parents have to do as well, was actually we co-slept with Zach for a little while after the surgery, just so that he felt safe. And the first time, I was sort of like, oh, I don't want to start habits.

And, you know, I want to comfort him and give it to him. But we should keep trying to put him in his cot after a feed. And, you know, if he cries, then we'll bring him into the bed.

The second time, we put him in his cot when he first went to bed. But as soon as he woke up the first time, that was it for the rest of the night, he was in our bed. We didn't even try and put it back in the cot.

And he slept so much better. Yeah, well, it makes me think about two things. The one is quite interestingly, when I was studying occupational therapy going back in the day, the very, very first piece of research that I had to synthesise and report back on was the effect of hospitalisations on infant sleep and on play, which was really interesting, because, you know, I'm kind of doing a full circle like 30 years later.

Yeah, it's about 30 years. So it's really I mean, and it does have an impact. But one of the things that and of course, one of the things that we recommend is to reconnect and to get that that kind of attachment going again.

And the one way would be to co-sleep. And I'd like to come back around to that topic just now. And the other one is a strategy that I use a lot with parents who've had little ones with some sort of separation issues.

And that's called watch, wait and wonder, which I think I might have spoken to you about before with Zach, with Max. And watch, wait and wonder for other mums context is it's when you literally just spend 15 minutes minimum time with your child with absolutely no distractions. So cell phone out the room, door closed or open, but certainly in a space where you don't have no distractions.

You take a specific box of toys down off a shelf that is specifically put aside for this purpose. And so there can be a couple of favourite little toys that can be dollies and, you know, imaginary play toys and then blocks and whatever it is. And then you literally just watch your little one play and see what they do.

And very often in those moments when they are, you know, kind of just playing around and engaging you and then not engaging you and just playing. It's just knowing that you're sitting and watching them that is a huge thing for them. And it does tend to reconnect them and feel a little bit more secure.

And interestingly, actually, I mean, obviously, with Zach, the first time he was five months old, so he was that little bit younger. But and we co-slept with him, obviously, for that reconnection. But where that watch, wait and wonder comes into its own is actually with Max post-surgery and post-hospitalisation.

The first time I massively underestimated the impact it would have on Max. That actually is what almost made the whole thing a bit more challenging post-surgery. I think I expected it to be hard with Zach.

You know, I knew that that was going to be tough. I knew he was going to be in pain or distressed or, you know, whatever it might be. But I hadn't really taken into account the impact it would have on Max and that reconnection that he was going to need, but also that feeling safe, feeling secure.

It doesn't matter how much we had prepared him or told him it was OK. Zach was OK. He has eyes.

He knows Mummy and Zach disappeared. And then when they came back, they went to this place called the hospital. And when they came back, Zach looked different.

He was crying more. He was, you know, Max is old enough to understand that swelling and bruising and scabs and things like that mean a lot of good things. And so suddenly Mummy and Zach came back and my baby brother, and I have to say Max adores his baby brother and is very protective and very sweet with him.

So that was very distressing for Max. I had massively underestimated that. And I think it's given me a real insight to Max's personality.

He's a very sensitive child. Very interesting. And so did you do so much wait and wonder with him? Yeah.

And we made sure that I, you know, sometimes it would just be a case of I just took him to the park without Zach. Somebody else had Zach. And, you know, we just sat and looked at the ducks together or we sat and went for a coffee and chatted together.

And, you know, he just had some quality, lovely time with me or with Daddy. And we just worked very hard. But it was definitely something that we managed differently the second time around.

We actually didn't tell Max the second time around that Zach was going to be having surgery. We talked a lot to Max before the first one. But the second time we decided not to tell him because we just we recognized that actually the way he works and this is him as an individual, we didn't want to create that anxiety in the lead up to it.

You know, that sort of, OK, well, they've gone now to the hospital and that's bad. If we lived in London where the hospital was, I think we would have taken Max to the hospital before it happened so that he could see the environment. The nurses would have made a fuss of him.

He could have gone for a play and things like that. But so that it wasn't a scary word that he associated with something horrible happening to his brother. Yeah.

One of the things that obviously got thrown out the window for a few nights was sleep. And you articulated something that is a massive fear, not just for mums of, I won't say a massive fear, but it certainly is a little niggle, more than a niggle for some mums, big for me, of babies co-sleeping with them and becoming dependent on them for habits. Now, I traveled a little bit of your journey with Zach, a lot less than Max, but I can remember right at the beginning, he would only sleep if he was on your chest.

So he was contact napping. So we had a situation with all day sleeps were contact napping in the early days. And now you're talking about later on, you had to do co-sleeping in order for him to sleep, especially after the hospitalizations.

Now, for many mums, including me, you would be thinking, oh my goodness, whatever people say, I'm making a rod for my own back. I'm going to be doing this. I'm going to be co-sleeping for the next 15 years.

I'm going to have to sleep train. But the reality is that that has not been what has happened because he's nine and a half months old and he sleeps through at night. So how did we get, what do you think your secrets were to getting him from being a contact napper and co-sleeping at night after hospitalizations where those didn't become a major theme of your life? So the first thing, and I think this is the case, this is nothing to do with sort of talking about it earlier.

This has nothing to do with even hospitalization or cleft. I know that I know other mums whose, their babies will only do day sleeps on them and that sort of thing. So I found that really hard, especially as Max had been like, you just put him in a sleepy head from a young age and he would just fall asleep for, sometimes we'd have to wake him after four hours.

You know, you're kind of like, you need to be. It was a very different story with Zach. And I found that very hard because I felt like I completely lost any independence at all.

But the first thing I would say, so during those early days and post-surgery, surrender to it. I think that that's like the biggest piece of advice I can give any mum in the early days when they want that contact, don't fight it, just completely surrender to it, actually enjoy it. It's a really short period of time and unique period of time.

It's not forever. It's not. And you'll miss it when it's gone.

Like there are times when now that Max, sorry, Zach does sleep, you know, through the night in his own cot. There are sometimes when I look at him and I'm just like, just, do you want to just come in and have a little cuddle with me? I really miss these little snuggles. You know, and after the surgery, there'd be moments where he was lying in bed with us and he'd just reach out and touch your hand and then fall asleep again, just to be like, are you there mummy or daddy? You know, and those are moments that I do miss.

So the first thing I'd say is just surrender to the early days and don't fight it because it isn't forever. Zach, once we gave him the ability to self-soothe, and by that I mean doing some very gentle sleep coaching at around the four to five month mark, he actually loved sleeping independently. He just, until that time, obviously he couldn't self-soothe.

He didn't have the skill set and it was too early to give him those skill sets. But from the sort of four to five month mark, we started to give him, help him gain those skills. And actually he's loved sleeping by himself ever since apart from sleep post surgery.

I mean, I have to say, we did everything the same with Max and Zach, and Zach is just naturally a better sleeper than Max. We've done the formula. Sick and born, I think.

We just sweat things less. And so it's less amped, it's less, you know, less emotional. And I definitely respond, you know, it takes me longer to respond to Zach either because I'm busy or because I know that he's going to be okay.

You know, with Max, I think I felt the need to get up at every noise a bit more or I had to really work on not going to him. Whereas with Zach, I'm very tired. I'm just going to give you five minutes, maybe you'll self-settle.

And he does. I mean, even now, still there'll be half an hour where he'll be making noises in his cot at 2am. But if he's not crying, I don't go to him.

But I'm more relaxed at doing that with the sick and born. So we did some gentle sleep coaching at that point. It was about four months because it was before surgery.

Then after the second surgery, that still, I was like, oh, we've done so well. He's sleeping quite well. Now we're going to go backwards and how we can get out of this.

But actually, Zach told us when he was ready to no longer be in our bed. He just, and I don't know if this would be the case for all children, but for us personally, there was definitely a time where he might even cry. And I'd say, oh, I'll bring him into bed with me and we'll have that lovely snuggle.

And he would just be restless and not want it. And then I'd put him back in the cot after a bit of cuddle, settle, and he'd be much happier to go back to sleep in the cot. So I kind of followed his lead on that and he did it.

And then by six months, so a month after the first surgery, Zach started sleeping through the night. And then my husband was very worried as we came to the second one, because he was like, what if that, what if we lose this forever? What if he never sees through the night again? Because he thinks, oh no. But again, a month after the surgery, he's back to sleeping through the night.

So, I mean, I'm saying this, Meg, he's going to wake up all night tonight. Of course you can never ever tell. But yeah, I mean, look, it's been absolutely amazing.

And he is, I mean, one of the things you feared was that you would lose that baby that you had before the surgery, because he was going to lose this wide open smile, which was just a spectacular, all engulfing smile. And of course he does look very different, but he was gorgeous before and he's gorgeous after. Did you find that, did you grieve his new baby face, the original face or did it just evolve and you were fine? It definitely evolved and I was fine.

I think initially it is difficult because you go from the really happy wide smile to actually, you know, the sore and it's swollen and it's a bit scary looking. But once that sort of, but even then, actually you go into autopilot mode of, I've got to care for my baby. You know, I've got to, and actually one of the other things that they advised us to give him three hourly pain meds.

So alternating urofen and paracetamol every three hours for first three to four days and the first time we were waking him in the night every three hours to do that and that was a real mistake for us personally again you know I'm not but the next time I spoke to the medical staff and I said look I really don't want to be waking him if he's asleep because it caused all sorts of problems last time and they said look it's fine just he will wake and give him the pain meds and that really helped but the the reason I sort of mentioned that is because you are you're kind of in this like right every three hours and then I've got to feed him and I've got to make sure he's getting this amount of liquids and I've got to do this and do that and so you're almost not able to grieve or you're going through the motions yeah you're a nurse not a mum in that moment and in a way that kind of it helps because you can't be too emotional about it all. As I say now for me it's if I have on my phone every hour the photo changes and so it will be a different photo of the boys and so I will get old photos of Zach and there will be I catch myself every now and again looking at a photo of him smiling with his old smile and I do think oh do I do miss that but he is still super smiley he's still got the most amazing smile because his whole face smiles it's not just his his mouth and he is just so happy I can't be sad because he's so happy it's infectious so that's and I think that's you know he just loves life and I think I almost am inspired by him to not dwell on it and you know he's bounced back and he's the one actually went through the surgery so come on mum you know quite exceptional and you know he really you did describe it there if people could see him they would understand that smiley eye face because he smiled with his eyes from the day he was born you know there was the rest of the smile but it was his eyes and that hasn't changed so incredibly special Cass and just lovely to really catch up with you to hear about your news they're gorgeous boys and we yeah we really appreciate you sharing a very different journey so while the first journey was very textbook and every mother could identify this one not as much but so many mums will go through hospitalization for some other reason and this has been really useful yeah and I think I often look back retrospectively and the hardest challenges really that we've had on a general basis with Zach every mum has them in some way and I remember saying to a friend of mine here I said oh you know because of the cleft Zach this happens and that happens and she'd had a baby at the same time she said well I don't know what my baby's excuse is then because she's doing exactly the same thing and she doesn't have a cleft exactly oh yeah okay this isn't actually anything to do I know well I mean just the contact napping the fact that he always needed to be upright on you I mean many babies do that it's not that had nothing to do with the cleft although I think we kind of felt that maybe he was a little bit more uncomfortable but he probably wasn't he didn't know any different yeah no I think I was I was trying to sort of find reasons so that I could be okay with it because I found it really hard I know it is really hard yeah excellent well Cass thank you for joining us again maybe we'll catch up again in the next couple of months because I'd love to hear how the boys are doing we never got on to any of the things like development and the typical things but I think that it was a really good session just to chat about hospitalizations because that's something that so many of us will face yeah no definitely but no I love doing them so anytime I'm I'm happy to come back and chat about my children for ages brilliant I love it well the other mums all love you chatting about your children I've actually started a sequence with another mum Julia and she's got Aurelia who is four weeks old and she is following yours she has always followed your podcast so it really is something that people love plucking back into so thank you so much well no it's a treat for us because it means we've got this wonderful diary of our children growing up so it's wonderful absolutely pleasure well lots of love and thanks so much Cass thanks Meg bye thanks to everyone who joined us we will see you the same time next week until then download ParentSense app and take the guesswork out of parenting