Kiind Conversations Transcript

Episode 6: Grief and positive acceptance of diagnosis with Lucy Moran

Content Warning: This episode contains discussions of grief and other sensitive topics. Listener discretion is advised.

If you or someone you know needs support, links and contacts for mental health resources can be found in the episode show notes.

[Intro sound bite]

Speaker 2

Hello, Kaya, and wanjoo wanjoo. Welcome to Kiind Conversations, where we're simplifying the caring journey one conversation at a time. I'm Teresa Peer Navigation Lead at Kiind and your host. As always, we're here to explore the topics that matter most to parents and carers raising children with disability. I'd like to acknowledge that we are recording this podcast on the Wadjuk Noongar Boodja. We pay our respects to all Aboriginal and Torres Strait Islander cultures and to Elders past and present.

This episode is a bit different from the topics we've covered recently. Today, we're talking about the grief many parents and carers experience when their child receives the diagnosis of a disability or chronic health condition. Joining this conversation, we have Kiind Hospital Support Officer, Pauline, back with us.

Speaker 3

Hello.

Speaker 2

Hello. Now we know that this can be a complex and sensitive topic, so that's why we've invited Clinical Psychologist, Lucy Moran, from Chelsea Psychology here to share her guidance and expertise with us. Hi Lucy.

Speaker 1

Hello. Good to be here. Thank you. Thank you so much for. Joining us, OK.

Speaker 2

Thank you. Thank you so much for joining us.

Speaker 1

That’s okay.

Speaker 2

So Lucy, when we have speakers come in, we'd love to learn a little bit more about them in the beginning. So, we know that you are a friend of Kiind, or a friend of Kalparrin. So, would you like to tell us a little bit more about your story?

Speaker 1

OK. Thank you for having me. I guess my connection to Kalparrin as it was back then was in about 2011, and I was on a journey. I was studying psychology and I was discovering whether I wanted to keep going into clinical psychology. I had had a prior career, and I was having children at the time, so I was fortunate enough to work in PMH (Princess Margaret Hospital) and to work with Margaret Cole, who set up Kalparrin n the beginning.

And that was a really interesting and informative few years that I worked in the hospital doing all the things that I think Kiind still does in the hospitals now. And then it really helped me decide to continue with my studies. So, I did clinical psychology after a couple of years at PMH and at Kalparrin. And then I remained very close to the team I worked with, and I still see them all the time. And so I then continued with all the events that Kalparrin ran.

So, for a long time I was attending events with the families and once I was fully trained, once I was fully qualified, I was facilitating the Mum's Weekends and staying in contact with a lot of the families I've been on the journey with. So, I also obviously started working as a clinical psychologist for Kids are Kids Early Intervention Centre, and that was with a team of OT (Occupational Therapists) Speeches (Speech Pathologists) and physios (Physiotherapists). So, I did that for a long time, as well as the odd Kalparrin event, and worked in private practice. So, I continue now to this day still seeing some of those families because it's a journey. It's a long-term journey so.

Speaker 2

Yeah, absolutely. And I think the nice thing about, for us, I'm speaking for you now, Pauline.

Speaker 3

Thank you. Yes.

Speaker 2

Is that we do seek out to create a community of families. And we love that families are still with us, and we still make those connections, you know, from the point of when they became members till all of those different life points for them. So, it's lovely and so thank you for joining us.

Speaker 1

No problem.

Speaker 3

And I think some families, we see them when they're sort of right in the middle of, say, a new diagnosis or they're going for a really tough time. So, yeah. I think to see them along the journey where they, you know, might come out the other side and they're, you know, a lot more resilient or you know, they've built the confidence to advocate for their children and themselves and things like that. And, you know, it's really lovely to see that side of things too. I think down the track. So, yeah.

Speaker 1

Definitely. It's. very rewarding. And also you never know when people are gonna pop up and they do. I mean, speaking as a psychologist where we were never allowed to breach confidentiality with our clients. It's very different with the Kiind families because you bump into them everywhere. [Laughter]. And you're allowed to acknowledge them. Yeah, yeah.

Speaker 3

That is a nice part.

Speaker 1

It's a different journey.

Speaker 2

Thank you both. Lucy will be guiding us through grief and diagnosis and the impact it can have on families. Along the way, she'll also be sharing practical support strategies. But first, I'd like to acknowledge that grief is a deeply personal journey, and there's no right or wrong way to experience it. But we hope that by discussing it today, our listeners will feel less alone in those moments when grief does surface.

As always, the Kiind team is here to support you, our free Pathway Planning sessions can help you navigate the world of disability and access the supports and services your family needs. The link will be in the show notes. We also have a range of information resources to support you with this, including a guide on low-cost mental health and counselling support. You can find that in the show notes too. So, shall we get started ladies?

Speaker 1

Yes.

Speaker 3

Definitely.

Speaker 2

Lucy, I think it'd be helpful to talk about what grief is, and how it can feel to parents and carers raising children with a disability.

Speaker 1

OK. Thank you for that. I guess one of the things we're talking about here is more ambiguous grief rather than I guess the traditional definition of grief. Traditional definition of grief is around natural loss of a person. But when we're talking here, we're talking about a loss of a pathway or an expectation. And so ambiguous grief isn't always noticed by other people. It's something that you know, you experience as a significant shift, but everybody else is getting on with things. There's no funeral. I guess there's one way of putting it. So, understanding what ambiguous grief is, in itself.

Also, there isn't a clear label, so people might just say that they're struggling. They might just say that they're exhausted. They might just say they've got waves of confusion, and they just don't know where to begin. And they often turn that on themselves as sort of self-blame, when in fact actually they're grieving something. They're experiencing a significant adjustment to what they had anticipated. And there's loss. They're not sure what the future looks like. So, it's ongoing. It's not every day in the same intensity, but it probably varies over time. But I think one of these sorts of opportunities to talk about it is giving a name to it, so that perhaps you don't need to put it back on yourself quite so much.

Speaker 2

And there are some families that as well, don't like to put the label of grief on it, but they are still going to be experiencing all of those feelings, and so it's OK to not put the label on it as well, but seek out those supports - knowing that you're on that journey. And that it's okay to find help.

Speaker 1

Absolutely. Absolutely. I think everybody calls it what they need to call it, and everybody's at different stages of it at different times. So, there is a bit more, you know, whether it's denial or avoidance that can go on. There's also completely sort of, getting caught up in it. And then there's just coping, kind of in the middle, and I think, depending on where someone's at, they may or may not be wanting to talk about it. But even just reflecting on things are, you know, really tough or I just can't pull myself out of something. Well, maybe you're not alone in that.

Speaker 2

Yeah, yeah.

Speaker 1

And so that's the important thing I think is the actual communication of - what's really tough and what's maybe come up.

Speaker 3

Yeah. And I think it comes and goes as well, and you know, along the journey of the child that, you know, you might, you might get past one hurdle and you think you’re okay.

Speaker 1

You’re all good now.

Speaker 3

Yeah, and then something else will come up, you know, and that that will bring up those feelings again. So, I think that's quite natural. And yeah, just working through it at each stage as well. And yeah, finding those supports.

Speaker 1

Absolutely. Yeah, I mean, I do think, yeah, a lot of people might not wanna put the word grief to it. But also they don't wanna put any word to it because they like to think that they're managing.

But having a word that is actually not, it's emotive, but it's not judgmental has to be really the way you find your way forward because it's about actually accepting some things that you can't change, but that doesn't have to completely overwhelm you.

Speaker 2

Yeah. And I think the other thing, you know, we're talking about different kinds of grief is the experience that you have when a diagnosis is a complete surprise. As opposed to - there still might be grief, but you might have been on the rare undiagnosed journey. And so, it's a bit of a relief. So, you're feeling relief, but also acknowledging that there might be some other elements to what you're feeling that you might need support for.

Speaker 1

Definitely. And that's perhaps also comes out in, you know, how other people around you. It might be relief for you, but this might be a different stage for - partner, grandparent, that sort of thing. Because definitely, if you're feeling like you, you want to know what's going on, it can be a huge relief to have an understanding that creates a pathway to knowledge through a diagnosis.

Speaker 3

I know for myself that, as a personal experience, I actually liked hearing that word because it put a name to something for me that I wasn't sure exactly what I was feeling or what it was. Yeah, it was a bit of a relief that - Oh, that's what I'm feeling. OK. You know, that kind of, yeah, like I said, gives me a bit of a pathway and- yeah, bit of a way to manage it, so yeah.

Speaker 2

Thank you both. I think what makes the situation more challenging is that there's a lot of pressure on parents and carers to keep going, even though they may be feeling sadness or anger or the other emotions. There are still appointments to manage or new medical terms to understand. They might need to be the teacher for others around them as well. Like you were saying, you know, partners or family members that might not have been on the journey with you during this phase of exploration. And so, what guidance can you give to our listeners about managing their own grief?

Speaker 1

Okay. I guess some of the key points is it's going to be different for every person, so probably the most important for the person listening to this is to look after yourself and allow yourself to grieve. Allow time for it, and also recognise, like I said before, that there will be waves of intensity. So, whilst when we're sort of getting caught in a wave of it, it might feel like it will never end. It does turn around. The intensity lessens and another day begins, and you don't know what that's going to be like, but it is going to be something that you will just keep going with and it will halt the journey.

Your child will prompt you back into connection to going forward. But no matter where you're at. You're not gonna necessarily be across where everybody else is at. So often, what can be helpful in helping you get through it is, other people at the same stage or who've lived the journey. So, just connecting to others who've perhaps been through that, is really, really important. But I think the most important thing is to probably not just push it aside, and you know, any sort of self-blame or just sweep it under the carpet. It's no, just let it sort of happen. Take a deep breath, then try to reengage in them moment.

Speaker 2

I think, again I'm going to speak for you Pauline.

Speaker 3

Thank you. [Laughter].

Speaker 2

But I think a lot of families that we chat to, you sort of start the conversation with - What can I help you with today? What do you need as a carer? And they're like, “Don't talk to me about me. I just need to get these things solved because these are the priority for me. I'll talk about myself later.” So, recognising as well that you might just be delaying it a little bit. It's around the corner, so delaying also might have its own challenges as well.

Speaker 1

Yeah. Well, I think this sort of thing, emotional responses don't go away. You might be able to deflect them in the moment or distract yourself adequately to get through things in the moment. But you do actually have to take a moment to breathe and just acknowledge, you know, that was a really tough moment, or day or dread of a situation that's, you know, you've just got through somehow.

You know, and people are scared to do that because they just think they'll plummet. You know, they feel like the grief is overwhelming or whatever the emotion is, is overwhelming. And to stand in it will be, sort of getting caught and dragged down. When actually, you know it's a little bit counterintuitive if you just allow it, often it will pass a little bit sooner because you're not fighting it. You're not pushing it away.

Speaker 3

Yeah, I know that we've got a really great resource on our website and it's a factsheet called ‘Looking after you’ and it sort of, yeah, lists some points you know. And I know it can be really hard, but, you know, like taking some time out, or taking a break. And that's gonna look different for everybody. You know, somebody may be able to, you know, take a weekend away. But for others, it might even just be having a cup of tea and a snack. You know, sitting in the sun or -

Speaker 1

Or even just closing your eyes, right?

Speaker 3

Yeah, exactly. You know, just having a quick look at your phone or checking your emails or, you know. So, I think it's really important if you can try and you know -

Speaker 1

Just pause and -

Speaker 3

Do that as well. Yeah. And I think there was, you know, don't be afraid to ask for help. Sometimes, you know, there's people just waiting for you to ask. They might not want to ask you if you need help, but they're more than willing to help you if you ask, which can be difficult. But you know, if you know, if you can be brave enough and reach out, that can be really helpful. And I think, trying to keep healthy because you know, we're looking after so many people that we obviously forget to look after ourselves and yeah, to keep ourselves healthy, you know, not only eating healthy and exercising, but sleep. And yeah, just talking about how we're feeling to others and, you know, mental health is really important.

Speaker 2

Yeah, Lucy, are there some other things that you've shared maybe in in your practice with families who are on that journey as well around self care?

Speaker 1

Yeah, well, absolutely. If you can get time away for yourself. But I guess I talk about – it doesn't matter how big that time slot is. So it's taking a moment to sort of, walk outside, walk back in. If it can be that you can, you know, get away for half an hour and go for a walk outside. A lot of the sensory stuff I mean, I know a lot of families are very conscious of what the kids need from a sensory perspective, but for themselves, you know, a sensory intervention is a really beneficial thing, and that is a hot cup of tea. That is a change of environment around you. That is a shower. It is actually talking to someone, not listening to the voice in your head. It's engaging in your environment and if you can do that by touch, if you can do it by temperature, if you can do it by sensations that are sort of a bit more, bring you down to the ground, you know.

Then they are often the most beneficial in the moment to make it happen. It's a little bit of a reset and so it's taking those little and often through your day and then, yeah, if you do get that chance where you can duck out and have half an hour on your own, or get to a class you know, like an exercise class, or meet a friend for a coffee, or definitely get away for a weekend. [Laughter]. Any of those. But people wait for that to happen, and they don't do these little things along the way. I think it's more that it's actually beneficial little and often. More so than just the big things.

Speaker 3

Yeah. And I think also just to remind families that there is the Mental Healthcare Plan that they can, you know, reach out to their GP (General Practitioner) and I think it's around up to 10 subsidised appointments a year. So yeah, I know that sometimes financially, it's definitely difficult, especially now when things are so expensive for us to, you know, take that time or use our, you know, finances for ourselves. But yeah, I think that, you know, if they reach out to the GP and have a chat and, you know, even talk to somebody professional that, yeah, can obviously give some strategies or, you know, just someone to talk to that you don't feel like you're being judged or that's not in your family or that you might be able to say some - talk about things you might not with your, you know people that are directly around you and definitely things like that.

Speaker 1

Yeah, no. And also, the fact that often for me it's that I can refer them to networks that are not as expensive, so that it’s a pathway for that person to be cared for through things like Kiind, where you sort of think well, they're so across potentially what their kid needs, but they're just not looking after themselves. And. You know, connecting to listening to the right podcast, attending events that are actually gonna be compassionate and supportive.

Speaker 2

Yeah. And that's a good reminder we can pop it in the show notes. Even just a call to the Carer Gateway. So, reaching out and finding out what might, what little thing might be able to be taken off their plate so that maybe they can spend that time in a little bit of self-care mode. So, you know that you might be eligible to get a cleaner for a short period of time. Yeah. When the cleaners in your house go outside, sit in the garden and just soak up some sun, you know. Find those opportunities to create that space for you as well.

Speaker 1

Definitely.

Speaker 2

And I suppose it can be a little bit hard for families as well because. They're in this period of overwhelm, but it doesn't mean that that's constant either. So, they might be feeling a little bit confused that there's still elements of joy and happiness going on. Have you ever had or shared with families’ ways to really help them navigate that that ebb and flow of grief?

Speaker 1

Yep. Well, I think one of the things we forget is that humans are capable of holding more than one emotion at once. So, we can be feeling a multiple, mix of emotions. Now, if we're feeling angry, frustrated and annoyed, that kind of makes sense. But if we're feeling happy and sad, or if we're feeling grief and joy, you know, we don't often think that we can do that or that that one should gazump the other. You know - I should be happy, but I'm not. Or I'm overwhelmingly sad, but now I'm laughing at, you know, somebody's pulled a funny face at me. And it's actually, we have that capacity.

So, it's just reminding people that often put, I've got a deck of feeling cards and you know, you pass them to them and it's like, you know, pull out whatever you felt in the last 24 hours or what have you felt? What do you feel right now? And, you know, people can relate to a lot of different feelings, and it doesn't mean any one has to overwhelm them. But it's important to acknowledge them. And grief is something that will sit there. You know, dormant some days and a bit more active other days. But you're allowed to have more than one feeling at once, and often at the resilience comes from actually just sort of leaning into some of the mixture of feelings. So.

Speaker 3

And I think that can be confusing sometimes too. You know, it's supposed to be sad and you're laughing about something or you know, you're feeling like you said. You know, I should be feeling happy and I'm not. What is going on? But yeah, it can be. Yeah, a confusing time.

Speaker 1

Yeah. Also, I guess you know if you feel like other people are judging you and ‘oh she should be feeling a certain way’ and you're not. And you know how you're feeling. You don't have to perform for others benefit.

Speaker 3

Yeah, or you might, you know, have certain comments from people on the outside like, “Well, you know you're lucky” or, you know, “You shouldn't be feeling sad because of this.” You know? But everybody's journey is so different. So yeah, I feel that sometimes that's a little unfair.

Speaker 1

Definitely. Yeah, yeah, no. It's a complicated one. I think it's true for all humans though. But, particularly in this context. There's always a bigger mix or a more potent mix at times.

[Break music]

Speaker 3

Hi, listeners, it's Pauline here. We love being in the podcast studio, but what we love the most is seeing our families face-to-face at Perth Children's Hospital. Whether you're in for a routine appointment or you're staying with your child who's receiving treatment, our team is here to support you.

You can find us on the ground floor at the Family Resource Centre, or we can come up and visit you on the wards and check in and see how things are going. We're here Monday to Friday, 9am to 4pm. And if you'd like to find out more, you can email support@kiind.com.au. Now let's jump back into the episode.

[Break music ends]

Speaker 2

So that's some wonderful information and some strategies for families. Lucy, do you have any advice on how parents and carers can adjust to the reality of their child having a disability?

Speaker 1

Yeah. I mean, it's one of those things that parents may need to reconsider and start researching preexisting ideas of about what it meant. Because it's obviously not something they've understood in any detail. And therefore, often when we don't know something, we're a bit fearful of it. So, it is a bit of a reset. Now, a place that you can start to reset is things like the social model of disability as opposed to the medical model of disability. So, in terms of introductions to specialists and medical appointments, that kind of happens, but then seeing the world through a different set of eyes of like, well, how can my child, you know, have a full life and be able to experience everything? That's a bit more from a social perspective - looking at how can the environment accommodate my child better, rather than my child, either miss out or put up with a second rate alternative.

So, the United Nations actually have this as their mandate now, that this is the way they'd like to see disability considered. So, it's called the social model of disability. And it's basically, I get the definition right - that that the interaction of people living with impairments and the environment is filled with physical, attitudinal and or communication and social barriers. So, the onus is actually on the physical attitude and or communication and social barriers to work out how everyone can be included. So getting onto that sort of mindset is one way of starting to rethink “Oh well, there are gonna be ways forward” rather than perhaps getting caught up in the medical model, which is all about deficits and might be just, you know, getting your head around that. It's sort of like, well, what hope is there? So, it's that's one step.

Obviously talking positively from more of a strength-based approach which sort of fits in with that too. And I guess a key one is catching yourself in any sort of comparisons, which is a natural thing because we all have milestones and things that we're told to adhere to. And if we're not meeting them, then we're very sensitive to that. And I guess it's recalibrating sort of the journey you're on, and not then comparing back or comparing across the playground, or the school or that sort of thing. But I guess this is something Pauline's probably lived a little bit as well in resetting.

Speaker 3

Yeah, definitely. Just had a recent experience where my daughter, we were at a party and so there was a neurotypical child who was playing with dolls and, you know, walking over and feeding the doll. And you know, I guess just, you know, playing in a really typical sort of little girl way. And so, I was just looking at that little girl, and I did start to get a little bit emotional. Because I've had four boys and now you know, our little girl. She has got a diagnosis. And yeah, she doesn't really have a lot of interests. And yeah, she doesn't really enjoy or like to play with dolls and things. But, you know, that was my expectation was that we were going to play dolls and you know, houses and feed babies.

And so yeah, you know, I look at that and then, but I then I have to catch myself and just say, well, you know, we've got a different journey. You know, there are other things that she can do and that she does like to do that we do. So yeah, it can be difficult though. And like I said, she's, you know, I catch myself in those situations still and she's eight, you know, turning nine. So yeah, it's just it's like I said before, it's- yeah. Those things do pop up through different areas and when your child's growing up and you know, you're like I said, you think you're over it or you think you've gotten past something. And then, yeah, there's something else that pops up. So, yeah, I think, yeah. Just again that. You just work through it and learn how to cope and learn how to live with, you know, with enjoying and celebrating your child. Yeah.

Speaker 2

I love hearing her stories when she's incredibly cheeky or she has figured out some stealthy way of creating carnage. You know, it's celebrating those little moments. You're gonna have that mixed emotion of 'Ohh goodness. What has happened now?' [Laughter].

But also you have those moments, and I think I've had it with my sister as well. It's kind of like you can't really be upset. [Laughter]. Like, 'Oh, my goodness. Look what you have done. You know, you've been cheeky, you've figured out a system.' So yes, exploring all of those positives that come in that sort of come with that wave of mixed emotions.

Speaker 3

Yeah. And just some of those positives that come out of those really little moments that people take for granted, you know, like hearing 'mum' or hearing 'I love you' or, you know, like you said, just, you know, creating a complete mess and, you know, giggling about it and being, like, 'can I be angry at you?'

Yeah, just some of those little moments that people take for granted that you can really like. Yeah, hold on to and yeah, be happy about.

Speaker 2

Yeah. And I think we touched on it on in episode three as well in the podcast series when we were speaking with Rachel Callander. And it was about, yeah, finding those little moments in the journey that you can absolutely celebrate. And she shared a story around finding a way that her little poppet could be more mobile. And it was just such a lovely story of seeking out the strength, deciding what she would like for life, and then coming together and finding ways for her to achieve that.

So yeah, you know. You could be caught up in the grief of her not being mobile and not meeting that milestone of being able to crawl. But you know, then thinking outside the square, how do we bring joy and let's find a way that she can be mobile in her own way.

Speaker 1

Yeah, yeah, absolutely.

Speaker 2

And also, just going back quickly on the research. The other thing I was going to say when you were chatting, I think it's really great to listen to people who have been on the journey and an example for me is finding those Facebook groups. So, if we're talking neurodivergence, the Facebook groups written by and the questions are answered only by people who are neurodivergent themselves. It's such great insight and they offer lots of information on how they can be supported, how we can adjust environments to support everyone. And I think you touched on it slightly as well. There doesn't need to be much change for an environment to suit everybody. And so, if we can have a chat to people who have been on the journey, you know, what suits them? What have they learned as a person experiencing that diagnosis? I think we can learn a lot about how to support everybody.

Speaker 3

And I know we direct families to our Kiind Families Facebook Network as a real sort of peer support because there are so many families that are in those groups that are going through very similar journeys and have had the experience or are looking for recommendations or are looking for advice from families who have already been there or have had a really great experience, you know? And so yeah, that’s a really great place that we sort of send families to connect with each other.

Speaker 2

And it warms my heart, often. Not often. There's sometimes posts, where families hop on, they're not looking to have questions answered or they're not looking for recommendations, but they hop on, and they just explore their grief. Or they explore what's going on for them at the moment. And what I see is other families supporting. So, supporting the emotion, letting them know that it's okay to not be okay. And that they offer suggestions on maybe how they can explore those sad emotions that they're experiencing at the time.

Speaker 1

Definitely. Yeah, that I don't know if this is directly the same, but I do recall when the Facebook community first got set up and different people were sort of pitching in. But you know, people are very isolated in their homes, but they're also very isolated in hospital rooms. And one of the things that I remember happening in PMH was. - there was a bunch of different mothers in different rooms along a corridor or two at PMH. And they were on the Facebook community for Kalparrin at that point, and they found each other. You know, they were expressing something about, ‘Oh, it's another day’, or ‘it's another long night’ or it's a something’. And it was almost like, ‘are you in Ward 6 or are you in Ward 4?’ You know, and then they walked out into sort of a coffee room.

And they would never have found each other just because it was, you know, that that's what the internet. Well, that's what that sort of communities does. I mean, I know that happens on a suburban level as well, but that was just one of the sorts of the byproducts in the early days was people alone, sitting in a chair, they can't leave their child's bedside, but they can see that there's another lady in the next room sitting by hers. And they can then be there for each other.

Speaker 2

Yeah, yeah. Oh, that's lovely.

Speaker 3

Yes. And I think we also have MyTime as well, which is really great for those families that can't leave home, and they can register, and it’s run through the school term. We have different topics each week and, you know, families can register for free and don't have to register for all of them. You know, you can pick and choose as different topics there. So yeah, I find that really good for families to, for some support and to know that they're not alone, and to get some information and yeah.

Speaker 2

And even for, you know, if you are stuck in the room in the hospital, it's another way for you to make those connections as well. Yeah, yeah.

Speaker 3

Definitely.

Speaker 2

Thanks, ladies. Now we all know that a diagnosis can affect the whole family dynamic. Lucy, can you please give us some more insight into this, starting with maybe spousal relationships?

Speaker 1

Absolutely. This is a topic that that possibly warrants its own podcast. [Laughter]. So just to be brief - I guess the main thing with a spouse or partner is that they could be going through the journey differently and probably will be going through it differently because it impacts both parents. And when they come, I guess, particularly from different cultural backgrounds, either from each other or just from where you live, or wherever or generational perspectives, there can be a whole lot more complexity. But even if all those things are the same, there's gotta be, I guess, a level of respect and maybe creating a way to talk at a time when there is just the two of them. So, not having discussions in front of the child, really important. Making the time to actually say, you know, “what are we going to do about the next appointment or the way we see a situation.” And it's very hard to do because there's not a lot of windows of time.

But if there can be a priority on, you know, just how can we do bath time differently or how can we do when you walk in the door or when you leave in the morning, whatever it is - In a way where we support each other and we're respectful. Because different things press on different people and the minute people are defending their position, they're not listening to the other one. So, I guess, ultimately, with a co-parent and a partner, you're wanting to work together and when you've got times that doesn't work, work towards finding a way to. If again doesn't always work, and maybe whatever is possible within the relationship, achieve and then get other support elsewhere. Because sometimes just the lived experience of another family, another mother or another father, might be all that you can access. But that doesn't necessarily have to come between a partnership in raising a child. It just might be where we recognise we can't agree on something.

So that's in a little bit of a nutshell. [Laughter]. There's, I mean, obviously ideally, it's supporting people to get onto the same page.

Speaker 3

Yeah. And I think sometimes there's, well, probably a lot of the time there's one parent that's actually probably a bit further on in understanding or maybe seeing you know differences or attending more appointments, so they might have a bit more of an understanding. And so, the other parent maybe takes a little bit more time to catch up and be on that same page, or you know might need to, you know, like they just do their research differently or yeah, they need to find out the information differently. So yeah, they're giving each other a bit of grace around that. And then also the fact that male and females. Completely different in how they work through things or their emotions and feelings, especially around grief. So that's, you know, something to take into consideration as well.

You know, he might tell me off for this, but, you know, I'm the crier and my husband’s not so much. So, he might be really upset. He might be really, you know, feeling it, but I wouldn't know because you know, there's no tears from him and things like that. Where is me? If I'm upset, you know. Because I am crying and I am, you know, talking about it and things like that. So yeah. So just because they're not showing the same amount of feelings and things like that doesn't mean that they're not hurting or they're not confused or scared or worried as well. So yeah.

Speaker 2

In in your practice, are there different ways that you support dads and father figures?

Speaker 1

Yeah. Well, certainly, dads tend to be, not always, but the lesser involved in perhaps the beginning of the journey anyway of getting up to speed. And one of the things, I guess, is, you know, they both want the best for their child. So, I think nobody disputes that. But yeah, how they show it is different. So, connecting dads to other dads, I think is a- or to other sources of information because sometimes men struggle a bit with being told how it is. If it's really not what they wanna hear. And I don't mean that in a critical manner. It's more just, you know, they really want little Johnny to run up and grow up and kick a football or they really want somebody to be as they're seeing it, and maybe they haven't quite sort of got the information from sources that they put meaning into, they've got it from the partner, but that isn't quite enough perhaps in the journey that where they are.

So, it's bringing it back to what's going to work best for the child. The other thing and I think it ties back to what you were saying Pauline, is - In every relationship, there's sort of three parties. There's her, him and us. And she and he will display things and express things differently and be at different places, and that's okay. But it's how do *we* handle certain situations? So, it's, you know, that's what I mean by I guess earlier saying, you know, taking the moment to sort of go well, ‘this is what's going on for me.’ ‘This is what's going on for me.’ ‘How are we going to tackle it?’ And some parents tag in and out. They do just do that and give each other breaks in that way. Others allow one to take the lead for certain circumstances and it is a lot of give and take because some people have capacity in certain situations and others just don't, partly because some are more emotional and some aren't, and there's a strength in both.

I think that's, you know, sometimes the less teary can be more helpful. Sometimes, you know, teary is helpful, you know? So, communication and being respectful is probably what is the core, because then you remain open to each other, but keeping the child at the centre because that's the thing they're both working towards supporting.

Speaker 3

Going back to earlier, when we were talking about self-care and looking after ourselves and taking time. you know it can even be trying to take time for yourself as a couple as well. And you know, if you can't go out on a date night, you know, always create that date night at home or yeah, just sit and have, you know, like a real, a chat and make a designated time. You know, if even if it's 10 minutes. Just have a quick talk about how things are going and yeah, just to connect.

Speaker 2

And another thing I've shared with some families in the past is being able to, and I think it comes back to, you know record keeping is that if one partner needs to do the majority of the appointment - that you keep a little exercise book. So, questions for the appointment, outcomes from the appointment. So then when you're home or when you're having those moments where you can have a little bit of a date night or whatever, it might look like for you. Hand the book over so that the conversation doesn't have to be about the appointments. It can be about the other small things, that will bring that connection to them. And then the other partner who doesn't get to do all the appointments can still be kept up to date. And yeah, yeah, involved in the whole process.

Speaker 1

OK. Yeah, no, really good idea. Yeah, very beneficial.

Speaker 2

And so, I think we've, we've talked a little bit about mums and dads, but we acknowledge that not all spousal relationships are gonna be similar. And so there would be other challenges, other ways of supporting the spousal relationship, depending on what the family looks like. So, there might be single sex families that might have their own needs and acknowledgement of what that grief looks like for them. I'd imagine that there is, you know, things that we can touch on for single parent families and I imagine exploring grief in families who are co-parenting might be a little bit different as well. So, if we if we maybe start with co-parenting, I imagine that it's quite difficult if separated parents are on completely different grief journeys as well.

Speaker 1

Definitely, definitely. And again, depending on the involvement, particularly in the child's journey. I love the comment earlier about the communication book and involving both parents as much as possible in decisions about the child. And so even if it is, one is typically going to various appointments that equally information is available. I think that's definitely in the child's interest, but it's harder if there isn't the existing relationship still in place, because then those parents will also have grief about their family structure. And the fact that the family structure isn't what they had hoped it would be. So, there's a few layers. To families that are separated for whatever reason.

I think in in the sense of more diverse family structures where same-sex parents. I actually don't know that that would be that different because you are always going to have two adults going through what they're going through, leaning into each other on certain things and probably seeing the world differently in certain ways. So, I would say a lot of the ambiguous grief they're experiencing is very similar to what we've been talking about. But you know they're individual people, just like, like, any partnership. So, the more respect there can be around actually giving the other person a chance to express what they're feeling. And understanding when some people aren't as expressive, just finding a way. Because I think you know this is something that is ongoing and like we said, you just have to keep getting up the next day and you don't quite know what hurdles are going to set sort of emotions in play. So having an outlet that you know, even if you're sort of, you go quieter rather than more expressive that that's understood to know what that means, so that it's right. I can see, you know, you're needing to take a moment or you'll tell me in good time. Having a really good understanding, I think of each other would be the same regardless of the partnership that's together, yeah.

Speaker 2

And I think single parents as well, it's about finding other avenues where potentially they could – There's someone to bounce ideas off. There's someone to let them know when you're not having a great time. You know that might be your best friend. It could be family members. It could be people in your community. It's just about finding other ways for you to share. To get support and to work through what you're feeling on this journey.

Speaker 3

And you know, we've just started our new program, Parent Link, which we're connecting families that are going through similar journeys, whether it's around a diagnosis or the child's age or both. And, you know, having families connect and then being able chat. And I think that can help in talking to someone that it's probably not going to judge you because they're going to be having the same feelings. So yeah, we feel like that's a really great program and, you know, connects families and you know, if you are a single parent and you don't have that person to talk to, you know, making that connection could be, you know, really, really great, yeah.

Speaker 1

Yeah. No, definitely.

Speaker 2

And I think, yeah, when you're feeling isolated, it can be harder if you're doing the journey on your own and so acknowledging that as well. That you know, there you might be doing the work of two people. So, acknowledging that and realising you know, you're doing a great job as well.

Speaker 1

Yeah. No, absolutely.

Speaker 2

Thanks, Lucy and thanks, Pauline. And how about the child themselves? There may be a point where they start to notice that they're different from other children and want some answers. How can parents support them?

Speaker 1

Yeah, this is a question we get asked a lot. It's often a very difficult situation for a parent to know what to say. I guess the guiding principle I encourage people to do is just answer the question that's asked. Because kids when they want to know something, they let you know that they want to know something and when they've heard enough, they will often let you know. Parents or adults often want to over explain. You know, we come at it with 'I've got a phrase it right and I've got a, you know, give context and all this sort of stuff.' But if somebody is wanting to know, why is it harder for me, or why does this keep happening, or what's going on? Then they often just want little bite sized chunks that are I guess age appropriate.

So, I encourage people to meet the child where they're at and follow their lead. So, say something if they need more, they will ask more, and then you'll give more. But don't over explain. That's probably the main thing. And there are lots of books for lots of different conditions now that help in explaining it. There's also a lot of therapists, a lot of speeches, a lot of OT's, a lot of psychs, a lot of physios who are doing this all the time. So, if there's already an existing relationship, sometimes that can come up in that context as well, where it's just more from a curiosity base. That sort of thing. So, I guess it's working with what everyone feels comfortable with, and I guess the parent managing their own overwhelm in it, so that they're just present for their child. You're curious, you want to know about this.? Okay, what do you want know?

Speaker 2

Yeah. And I think sometimes, you know, children even might be experiencing some of the negative wording or the negative connotations around disability. So sometimes it's good to share, you know, the positives and the things that, you know the amazing things that come with it. And so, I think that, you know, being able to share with your child, you know, great stories, you know, cultural leaders, who also experience the same diagnosis is good as well to share that with children so that they they're not always surrounded by that negative definition of their diagnosis.

And I can see that also helping your child make connections with other children with a similar disability could be a nice thing to do as well of creating that positive space around their diagnosis.

Speaker 1

Definitely. Yeah. So, I guess depending on the nature of the disability and whatever you're connected into as well, there's certainly a lot of group type things that they can be involved in. Because a lot of these kids often, you know, if they're going there around a purpose, it can bring them together. It can certainly make a difference or yeah, if you can even just get connected with other families and meet and see how the kids go. And just, you know. Start to be experiencing something different from perhaps what they're experiencing at school or, you know, different environments that show them that there's lots of diversity in the world, I think.

Speaker 2

Yeah. And I think it's nice we get stories from families who maybe have hopped on 'What's on' or received the 'What's on' on Friday afternoon and participated in an event that might be, you know, really inclusive, supportive or sensory friendly or around diagnosis, and they tell us about just, you know, what an amazing experience it is. They get to feel comfortable. They get to know that they're not getting the judgement or the, you know, the people looking at them. But also, the children get an experience of yeah, you know, figuring out that they're not the only ones. And that there's some other kids out there with the same diagnosis that are awesome to play with.

Speaker 1

Exactly, and that's really, you know, all you're wanting to do is broaden the contexts that they're drawing conclusions from. If they're only hearing negative comments in a classroom, well then broaden the classroom. I mean, as a parent, they're always gonna be focusing on the strengths. But it's really validating if it's coming from a few other sources.

Speaker 2

Yeah, absolutely. And I think it's nice. You did mention it. But if you're if you already have a relationship with a therapist or with a medical professional - getting advice from them. Because I imagine they've supported other families who are trying to tread through this new diagnosis with their child. So, seek them out, tap into their ideas as well.

Speaker 1

Exactly. Yeah, accessing groups where there's a social component to learning can be a really helpful way for kids who struggle on their own socially so that you know that's perhaps where the typically developing classroom dynamic plays out. But if they can be in a context where it is supported and they come away from it, having really connected with a few people - That's what's going to give them, you know, the encouragement to give more things a go because you can do a lot sort of one on one with your child to sort of encourage them. But they really need the examples of coming away from a play date that did go well to want to go towards another one.

Speaker 2

Yeah. And I suppose a lot of those strategies as well would also support siblings. So, what other things can parents do to make sure that the sibling child doesn't feel left out?

Speaker 1

Yeah. Extremely important area. From the perspective of siblings, this is probably one of the areas that there's never quite enough done. And there's often just not enough time. So, in terms of supporting siblings, the most important thing is probably creating time. It doesn't have to be long, it can be just five minutes at the end of the day, if that's all that time permits. But it is around acknowledging the importance of the relationship with the sibling, and it's not about the other sibling.

It's about the uniqueness of the sibling, of them as a valuable member of the family and an acknowledgement that often their needs have to get overlooked or put aside in order for the family to get to things. Where possible, doing things that involve the whole family and where possible, doing some one-on-one things without the other child there. Connecting siblings to other siblings is a valuable journey. I mean, these are usually very compassionate people and they are all very caring of each other.

So, it just is what I typically say is, you know, just one minute more than you think you can manage. Because it's hard to find the times on some days. Some days will be windows. Make the most of those windows because the other child's may be asleep or busy. But it's, you know, siblings do feel it. They really feel it.

Speaker 2

There would be some siblings out there that are experiencing the sort of more physical side of you know, behaviours of concern. Have you supported families who are experiencing that challenge within sibling relationships?

Speaker 1

Yes, at both at the time and later, because I think this can have a residual effect on individuals if they've had that sort of an experience with their sibling growing up and even now when they're not living with them. I think what's really important is acknowledgement from the parents. In terms of support for the sibling, acknowledging what they're going through, and the fact that maybe they are getting a bit impacted physically by their sibling and that there's an acknowledgement that, you know, they're not responsible for inciting it. You know, because often there's a feeling that maybe, you know, we have to tiptoe. And then why did you sit so and so off? And that sort of thing. So, it's a very delicate balance in terms of understanding how people are turning it on themselves. So that's where I think maintaining really open, respectful communication with the other siblings, always hearing them out. Because they are going to have their perspective.

They're human, they are going to do things that perhaps they regret in terms of making too much noise or inadvertently doing things because they're just trying to be them. But I think the reality is they probably do cop a lot more. And they probably are very, very compassionate. And when they are really struggling, it's really important to find a way for at least one parent to be with that with them. And to sort of work with them around, how can we do this differently? How can we do these situations differently? What is the sibling's perspective? What's the parent's perspective? If you can involve the other sibling that's perhaps causing the physical impact that would be great too. But I think it's just the validation. A lot goes unsaid. And siblings often don't want to raise things and make more work for anybody, so they'll just sort of hold on and soldier on.

So, I think listening and involving discussions around how can we perhaps do this differently so that even if they're eight, or 10 or 12 or 16 doesn't really matter. They feel like, you know, we all live in this house together. We all get impacted. And other than that, that it is just working out how to coexist and support each other. But siblings definitely usually carry a bigger load than is recognised.

Speaker 3

We've had really great experience recently with Young Carers. My son, who is nine, he's getting some really practical supports. So, some counselling. And yeah, he thinks that he's so important. He gets to go off by himself and chat to somebody and it's just an hour where they talk about how he's feeling about being a young carer and that's private. It's kept between them. You know, I've said if he does want to talk to me, he can, but otherwise he's like, "no, I want to keep this private." You know, he feels that that's, you know, his time to express himself. And it might be things that he's not able to sort of express to myself and my husband. But then there, you know, there were some other sort of things where they gave him some other things where it's around respite, so he can go off to his room and build a LEGO set. So, he does get that, you know, a little bit of time. And yeah, so, you know, it's just something that I think, yeah.

Speaker 1

He's empowered a little bit to handle the situation.

Speaker 3

Yeah, exactly. And we try and keep things quite positive as well and say, yes, we understand that there's-there is a lot that goes around, you know your sibling and at the diagnosis, but then also let's have a look at the positive things that we get to gain from that as well. So I think that can you know, even there might be one positive thing, but you know you can point that out. Yeah. You know that might help. But yeah, I just really wanted him to talk to somebody outside of our family and start young. Yeah. Just in case he wasn't, you know, in case he wasn't able to tell us how he was feeling.

Speaker 1

Some of them want their appointment too. Like, the other one gets all the appointments. [Laughter].

So, I've had quite a few over the years where you know, their parent has recognised that and brought them their own space, essentially, and this is just about them, and often they will invite a parent into that space because, you know, they finally get to do that. It's only about them.

Speaker 2

Because I think not all families know that if you are being supported by an NDIS plan that there may be some potential where the family can go into the appointment. That the service, the assistance is for the person with the plan. But also, if it's the whole family working on strategies for example, that siblings can be part of those plans. And I know of a lot of therapists who do invite siblings into the sessions as well. So it's one thing to think about. And also, I think that, you know, the Carers WA siblings carer program is awesome. Siblings Australia are doing -

Speaker 1

A bit more now.

Speaker 2

Yeah. And they've got lots of information on their website and we actually created a document in collaboration with them around supporting a child when there's challenging behaviours around the diagnosis. So, we'll also post a link to that in the show notes so families can sort of build on those strategies and give them some ideas around sibling supports.

Speaker 3

And even touching base with the school and letting you know the school and maybe their teachers know how things are going, if you know, maybe they're experiencing a bit of a rough time. You know, if there's anything you know happening at home around a sibling and a diagnosis. You know, just to give them a heads up just so that they know that they could be, you know, dealing with a few issues and things like that, just so that people are aware, you know, if they're feeling a little bit sensitive or, you know, they've had a rough week or a rough weekend. You know, just so that the teacher can take that into consideration.

Speaker 1

Definitely.

Speaker 2

You know, I'm even thinking, you know, they didn't get a good night's sleep if someone was up because of a medical requirement, so the whole house was up. So, then that's gonna impact on siblings as well.

Speaker 1

Yes, definitely.

[Break music]

Speaker 2

Hi, everyone. It's Teresa here. If you're not yet a member of Kiind, now's the time to join. When you join Kiind, you get access to one-on-one support from a Peer Navigator, connection to other families, and access to information and resources to help you on your caring journey. The best part? Membership is free. Join a community of thousands of WA families raising a child with a disability by heading to our website kiind.com.au. Now let's get back to the episode.

[Break music ends]

Speaker 2

Thank you, ladies. We've spoken a lot about grief at the point of diagnosis, but there will be other times throughout the journey when those feelings will inevitably resurface. Lucy, can you please touch on that?

Speaker 1

Yes. Okay. As we sort of mentioned at the beginning, obviously there's the point of diagnosis, but then there's also going to be the point of diagnosis, the journey around it's not going to be the same is going to hit some hurdles, which are typically things like the choice of Kindy, the choice of school, another birthday, going to high school, leaving school. A lot of times when you know you've been in a pattern and you've got perhaps really comfortable with that primary school or that teacher, and then it all has to change again. And there's the sort of the reminder that this isn't as easy to deal with. So, these are sort of transition points that trigger a flare up in the grief process. What's important, I guess, is to not be so surprised by them, because a lot of people feel that they're probably in a pretty good place for a period of time until one of these sort of comes up and trips them up.

The other thing I guess I've just alluded to sort of like anniversary dates or predictable dates. Right, is more the unexpected ones like the comment from someone or just like what you were saying earlier, Pauline, about noticing a little girl doing something or it could be just something in the sensory environment. You know, it could even be just walking through the supermarket and you hear someone else dealing with something. And there's a ‘oh yes, I've been there or I'm still there.’ Sort of moment.

So, I guess initially it's just be warned that this is a journey and that this is going to flare up from time to time. When it happens, same sort of thing as what we talked about earlier, the self-care and the messaging to yourself. It's sort of pause – 'Ohh I'm here again.' And it's true, it's real. This is feeling really uncomfortable and it's a reminder that the journey deviated from where I wanted it to be, or it's, you know, I'm seeing my other friends child graduate or something, and I don't know if my child will graduate that sort of things along the way. It just shows you how important your child is in many regards. That you've you know, you've thrown a lot into, you know, embracing their journey. But there was a part of you that wanted something else for them.

So, it's very necessary, but it's also something you have a choice about how long you stay in. You don't have a choice that will happen. It will happen. You have a choice about how much you get caught up in it. And one of the ways I sort of describe managing, I guess, rumination and problematic anxiety is, you know, well, you can go and sit on the couch in an isolated room and allow the thoughts to overtake you and the feelings to overtake you. Or you can get back off the couch and start playing with your child, or get out the front door and get moving again. Yes, acknowledge it, but keep moving. You get to choose how long you sit in it - is the part that you do have a choice in.

I guess that's the main thing. I guess the self-care when you can see it coming, you know, maybe take a moment on it on a birthday, or on the day before the first day of school or, you know when you know, these transition points are coming. I mean, you'll learn. By the first couple that you can predict some of them. But that's essentially, you know if you can go a bit easier on yourself. You'll get through them, and you'll probably pick the people you wanna be around for them.

Speaker 2

Good point. And I imagine it's making connections with help.

Speaker 1

With help. Yeah. So, some people do like to just sort of manage it on their own. Some people know that they actually aren't good if they do that. So, the people that will understand will be the others that have lived it. So that is likely to be the someone in the Facebook community. Someone you've met on the journey that that has gone through the same thing. It might just be a grandparent or a partner or someone that we – 'Oh yeah. It's one of those days and that's why we're feeling like this.' That sort of thing.

Speaker 2

And you know, knowing in advance those support services as well that are out in the community. And they all don't have to cost a lot of money. There are free and low-cost options out there as well. Definitely, yeah.

Speaker 1

Definitely, yeah. And certainly something like Kiind, you know there's always somebody listening in the Kiind Facebook community or at the end of the phone and often it might be – 'I'm just frustrated. My child's teacher, won't, you know, listen. Oh.' This is about it being the first day of a new year. Yeah, and that's sort of a part of this, you know, so it's kind of organising it a little bit because often we want to blame things, but it's just that sort of reminder.

Speaker 2

Yeah.

Speaker 3

Yeah. And we do have families that do call, and they can be upset and frustrated. And I think what sets us apart is our lived experience. So, they're not just talking to somebody that's reading from a script or has, you know, just read a book. You know, we've either been there or we're going through the same thing. So that, yeah, I think they feel like they're connecting with somebody that understands. And yeah, is there for them to support them.

Speaker 1

Absolutely. So maybe Kiind puts more people on the phones, those times of year. [Laughter].

Speaker 3

Well, I know for myself when my daughter got her very first school report and having, you know, other children that, you know, had just received your typical school report and then seeing my daughters, which was very, very simple, very broken down and you know, also because she had an IEP (Individualised Education Plan) and, you know, sort of, you know, limited speech and Kindy, wasn't able to sit at a desk for more than five seconds and things like that.

I just burst into tears when I started reading it, I cried and I cried and I cried and it really surprised me because I knew it was going to be different, but I wasn't expecting to get so emotional and upset over it. And yeah, then I just had to sort of bring myself back and just say, look, you know, this is what it is, you know, and these are around celebrating the things that she can do. And this is working towards things that she can do and just try and make that positive. But it was definitely something that I wasn't expecting to feel.

Speaker 1

Took you by surprise.

Speaker 3

Yeah. And that was a school report. So, you know, there's yeah, things that just those little things that can be quite triggering. But then, you know, the bigger things you might sort of power through so, yeah.

Speaker 1

Yeah. Yeah. We're always surprised by the intensity of emotions, I think. And that's what throws us because we think we've got a lot under control until something like that happens.

Speaker 2

Yeah, yeah. So, grief is very complex. And this might it take some time for families to work through together.

Speaker 3

You know, I just want to remind parents, carers, family members that - They're amazing and they're doing an amazing job and a lot of the time they're, you know, advocating for their child. You know, they're keeping appointments, they're, you know, doing all these wonderful things that they don't realise that they're doing. So, you know, just to remember that - You're doing a great job. You really are.

Speaker 1

You're doing enough.

Speaker 2

And I think when we're, you know, we're touching on the acceptance of grief, it doesn't necessarily mean that we're just gonna be instantly happy either. That you know, you chatted about how this is ongoing. You know, what can families do when they're really, still not sure how they should be feeling?

Speaker 1

It's great if they can talk to someone supportive perhaps that's not quite in it. So, that could be, you know, someone who's just got lived experience, who's just a little bit removed. The hard thing with families, if they're all grappling with it, is that they actually can't hear each other. So that's where it can be really helpful to talk to someone independent, whether with lived experience or in a professional sense, where it can be just sort of, like I said, with the emotion cards I sort of lay them out. You don't even have to say them. You know which ones feel right? And then we can organise them. You know, it's a little bit detached from, you know. Like, some people say, even especially parents, you know, the minute they start to talk, they well up, and then all the emotions are on top of them and then trying to organise that for the sibling or the other individual or partner or anything, you can't do it.

But if you're with someone who's just giving you a way to express it in a more manageable size, then it's easier to actually accept. ‘Oh well actually there are other emotions going on here.' And you know they actually regroup a lot quicker. And some families I know have taken the emotion cards home and it's you know, what's everyone feeling and they hand them out. So not having to necessarily express it in words in the intensity of the emotion. It can be, you know, you're able to go to your room and just do it your own way. I'll check in with you later.

When we're highly aroused, highly elevated in our mood, it's very hard to articulate in a way that, unless someone else is not up there with us. So as a parent, obviously we have to try and get ourselves back down to be able to be there to hold our children's emotions, that's why I say it's very hard if there isn't someone a little bit external. And that's where you know what you guys do makes a really big difference. It's very accessible and certainly even like the Facebook community, even just being able to express it in writing quickly. 'Has anyone done this?' Yeah, and for, I mean, I often say to people between sessions, you know, if something's really bothering you, write me an email and they just get it out of their heads. And I said 'You can send it, or you can not send it. See how you feel when you've written it, but organise it, get it out of there." And that that can be another way within families.

Speaker 2

Yeah.

Speaker 3

And what about parents blaming themselves? I mean, especially I think mothers because, you know, if they've carried the baby themselves that, you know, a lot of the time, you know, you can't help. I think it's just human to, you know, even though the doctor might be saying there is absolutely nothing that you've done wrong, you couldn't have done anything differently and your child will still have this diagnosis. How do parents sort of navigate that?

Speaker 1

It's a really hard one. Again, I think acknowledging that they're doing that is probably the most important thing. So that is being able to express it to someone in a sort of nonjudgmental setting. I think they'd find that they wouldn't be alone in that, but actually it's okay. Well, we know you love your child and we know you're harbouring this, this guilt, this feeling of blame. And that's a potent and large emotion. And is that really helping anything now? And it's gonna be there, but we can dial down how important it is and how much we attribute to it.

So, I think it's natural because we would all do anything we possibly could for our children and to think that we could have done anything differently, we would have. But that happens in life, you know. Do you cross the road fast enough? Do you sprinkle salt on your dinner? You know, there's so many ways you could get caught on that. And again, this is when I say you have a choice how long you stay in it, the thought might come up. The feeling might come up. Acknowledge it. Is that something that's really going to help me be present in going forward with my child the minute we're caught in blame, we're not available. We can't be connected with, certainly by our child. They're like “Mummy, do this or Daddy do this.” And it's like caught in a spiral of negative thinking and self-blame. It's very, very detaching. And I think if you can see it from that angle, it might be helpful to be able to go. “That is the last thing I want to keep doing, and I do have a choice about that.”

Speaker 3

That's great.

Speaker 2

And that ties into the yeah, that whole acceptance as well. And that the acceptance of the part of the journey you're in but also making sure that you get all that help, all that support that you need. Because even at the acceptance phase, there still might be some things that you need help with or want to talk through.

Speaker 1

Definitely. And the more self-care there is, the less you will slip into that. You know, you'll be able to hold the perspective a bit better. It's more when there's depletion on the - overtired, not fed well, not well watered, parent is going to be more sort of self-sacrificing, more self-depreciating. In that headspace and harder to get out of it. So again, that's the choice we do have. Not that we get these thoughts. [Laughter].

Speaker 2

So, we hope everyone listening is feeling more supported to understand and navigate their own grief journeys. Lucy, in every episode, we leave our listeners with one last Pearl of Wisdom. What's the main thing that we've shared today that you would like families to take away from the episode?

Speaker 1

Okay, it's probably not gonna come as any surprise that it's all about self-care so that you can be the best version of yourself more often with your child, essentially. Grief is a part of that, but it's not all of it. So, I guess accepting that there's going to be a part of you that will always feel some of these emotions. It will help you cope with the fluctuations if you look after yourself and don't let the resentment, frustration, sadness build up. Acknowledge them. But then it's okay, well, they're a part of this journey, but there's actually all these other emotions in there, too. And I have a choice. You are the most important person in the child's life, in *your* child's life. So you want to be present for that. And a lot of this other stuff can really take you away from that. So, I guess self-care is the key.

Speaker 2

Lovely, lovely Pearl of Wisdom. And Pauline, what's your Pearl of Wisdom for this episode?

Speaker 3

I guess mine is on trying to focus on what your child can do rather than what they can't do. And it might be around sort of changing your expectations a little bit. I know for myself. I, you know, with having four boys and having a girl, I had all of these expectations around what we would do and what we would do together. And you know what she would love and things. So yeah, I got I really did get caught up and I still do get caught up in all of those things that we will miss out on or we can't do. So, I really have to change my thought process around that and one little quick story that I've sort of started doing with my daughter.

You know, I think it's around, you know, having mummy-daughter days. And I go to the shop, and I see, you know, a mum having a conversation and my daughter's nonverbal. So sorry. I'll try not to get too upset around this. But yeah, just. I always thought that we would go and have our nails done and we'd chat and we'd have, you know, snacks and things together. So, I was at the shop one day and I go to a nail place and there's a really lovely lady that owns it and I thought, 'How can I make this experience so that I can share it with my daughter how she would like to do it?' And so, what I've started to do is every time I go to the shop with her, we go into the salon, and the lady knows us quite well now. I explained to her my daughter's, you know, disability and her sensory needs and stuff. And I said, "look, she's probably never going to have her nails painted or anything like that." But we started going in and she sits on the chair for a few minutes. She has her iPad. So, I sit next to her and, you know, we just looked around the room and then the next time we go in. You know, she'll put her feet like, dangle them over the edge.

And so, yeah, I guess I'm just hoping that one day, that I'll be able to get to the point where we go in for an appointment and I'll get my nails done and she'll just sit there happily. She might maybe put her feet in the water or something like that. So yeah, it's just something to experience together and it might not be what I thought it was going to be, but I still I don't want to miss those opportunities with my child, and I don't want to look back and think why didn't I try? Why didn't I take her out? Why didn't I do these things? So sorry. Yeah.

Speaker 2

Yeah, that's lovely Pearl of Wisdom.

Speaker 3

Thank you.

Speaker 2

That brings us to the end of the episode. Lucy, it's been wonderful to have you here. Thank you so much for joining us.

Speaker 1

Thank you for having me. Great.

Speaker 2

And thank you again Pauline for joining us.

Speaker 3

Thank you for having me.

Speaker 2

For links and resources mentioned in today's episode, check out the show notes. Don't forget to give Kiind Conversations a follow or share this episode with someone who may need it.

The Kiind team is here for you. If you'd like one-on-one support to help you navigate any issues that your family may be dealing with, you can book a free Pathway Planning session with us. The link will be in the show notes.

We welcome all your thoughts and ideas. You can email them to hello@kiind.com.au. Thanks for joining the conversation with us. We'll see you next time.

All together

See you later. Bye.

[Outro sound bite]