

## Rachel Callander Sees Superpowers by Nathan Scolaro

Nathan Scolaro speaks with Rachel Callander

Rachel Callander has a room of healthcare workers in tears when I hear her speak for the first time. I'm at the Gathering of Kindness—an annual conference founded by Dumbo Feather alumni Catherine Crock about bringing more empathy and compassion into healthcare—and Rachel is sharing the story of her daughter Evie, who was born with a rare chromosomal condition.

Named Evie Amour, which for Rachel and her family means, “Life is possible because of love,” Evie was constantly in and out of hospitals for tests and procedures, and Rachel became attuned to the varying ways medical staff communicated her daughter's condition to her. She saw how powerful words were in highlighting Evie's humanity and enabling her potential—and made a conscious effort to shape her child's world using open, empowering language as much as possible.

Rather than seeing limitations in Evie, Rachel saw superpowers—unique ways of engaging people and interacting with the world. It inspired her to meet others like Evie, so she set out on a trip around her home country of New Zealand learning from children with similar conditions and capturing their stories using her camera. It resulted in *The Super Power Baby Project*, a large-format coffee table book featuring joyful, striking portraits of 72 children, as well text detailing their qualities and life-changing powers. The work has won several awards, and taken Rachel to the TEDx stage and numerous conferences around the world speaking about the relationship between language and human potential.

What is so moving about Rachel's story is not how close to death she's come, it's how close to life. Although she's experienced profound grief and loss, she has seen humanity and abundance in typically unseen places, and told people to look, to pay attention. When she speaks, you can hear joy and pain all at once; this is clearly someone who has felt the extremes of life and held the tension. A photographer, painter and writer, Rachel uses art to penetrate the categorical ways in which we view the world and create a universal language of belonging and connection. While she works closely with words, and advocates for more empowering language to be used in healthcare, she also believes there is more to communication than what we say. That's one of the many lessons Evie taught her. That when we quiet the mind and feel into the connection, there's actually an entire conversation going on right there between our bodies.

**NATHAN SCOLARO:** So let's talk about the work you're doing now and then journey back through your story.

**RACHEL CALLANDER:** Okay cool. My work involves speaking to health professionals about the need to communicate with patients using openhearted language, especially at

diagnosis. I teach how the first words used at diagnosis critically shape how a patient or parent or family member perceives the present and navigates their future. These words can either help the individual be their best self through this challenging time and find meaning even in pain, or they can create anger, mistrust, frustration, and break down the crucial relationship between with the health professional. So essentially it's a conversation about empowerment, and how language can elevate those critical exchanges for the patient and for the health professional. And I'm not a health professional at all, I should say. I studied fine arts and have a photography background. I was a wedding and portrait photographer for 10 years in New Zealand. My first major experience with the healthcare system and with disability was in 2008, when my daughter Evie was born. She had a very rare chromosome condition,

"and what I noticed after she was born was that the language I was using about her and the language that the doctors were using was very different."

And I liked my language better [laughs].

[Laughs].

Because it highlighted ability and it highlighted humanity—whereas theirs was very negative, deficit language. And it took all of her ability and potential away. The healthcare professionals would use these cold, horrible phrases—like she was “incompatible with life.” I'd just given birth and was an emotional mess coming to terms with what they were saying and then they would use words like “mental retardation,” “abnormal,” “dimorphic,” which just seemed to exasperate everything. None of their words made sense. Their words didn't sound like they were describing a human being.

And you're not in a position to challenge them either—when you're already vulnerable.

Yeah, I felt very small a lot of the time. And I just expected that was normal, that they are the heroes. I remember one of the first pediatricians we met was trying to explain chromosomes to me. We had been living in the Neonatal Intensive Care Unit for two weeks and Evie had undergone so many tests, and he was trying to explain the long and short arms of the chromosome, the nature of splitting and how it all works. I was sleep deprived, recovering from a caesarean and emotionally exhausted, and I thought he was telling me that Evie had short arms. I was really confused because her arms were perfect! They were a perfectly long length! I thought, Why, on top of everything else that was going on in her fragile little body, were they so focused on her arms anyway? Surely her arms were the least of our concerns! Then he used a library book metaphor to explain how Evie's condition actually came from my own chromosomal translocation, which was more new information to me. All of a sudden I was thinking about library books, short arms and the mysterious behaviour of chromosomes, and I had no idea how to make sense of it all. The pediatrician's manner was really brusque and impersonal too and I decided then and there that I did not like this man at all. Which meant nothing he said after that landed. I heard nothing. I couldn't even remember what Evie's new diagnosis was called—let alone how to spell it. I was so confused, and didn't know what questions to ask. Then after a while I thought, I don't think this is how it has to be.

So tell me what you saw when you looked at Evie. Who was the little human you saw staring back?

Evie was the embodiment of her name. Her full name is Evie Amore, and to us that means "life is possible because of love." Evie showed us a completely different kind of love. Hers was a love without words. When I walked in to see her each morning, she'd see me and flap her arms and legs about in complete happiness. She giggled all the time. And she was mischievous. We would have friends around in the lounge room and she would slide down her bed, do a little back flip belly flop onto the floor, scoot along the hallway and pop out around the corner!

Ah! So cute!

Her love was freedom, pain, growth and wonder, all packaged up in a tiny fragile body.

So what was it like learning that Evie had this condition?

It wasn't a big thing for me at all. To be honest it was kind of liberating.

Yeah?

This is a funny thing. I was really nervous about being a mum. I just thought, I don't think I'm made for this. I love freedom and creativity and I felt that the way I wanted to parent was not really compatible with the systems of the world—education systems, career paths, life paths. And accidentally I fell pregnant and it took a while to get to the point where I was feeling okay about being a mother. Then Evie was born with all of these unique things about her and I just had this sense of overwhelming relief as well as the fear and the heartbreak of potentially losing her and her not surviving. But I had a sense of, Oh my gosh, we can live our life however we want. Like, there were no rules. The doctors couldn't give us all the answers because Evie's condition was so rare, so the relief came from her being unique I guess. We could do the parenting thing our own way. I love the fact that she was a complete anomaly, and we would be part of her unique journey—with her own set of rules and way of doing things. The layers of pressure and expectations just fell away. There was so much freedom.

So interesting. It's similar to how I felt when I came out as gay. It was this massive feeling of liberation because I didn't have to get married by this age, own a house by that age, do life the way society tells you. I could write my own story. Like, no one has written the rulebook for how to be a gay man.

Yeah! That's exactly how I felt as a mum with Evie. Growing up I had some health issues that made me think I could never have children. And at 13 I lost my granddad who was my biggest hero. That had a huge impact on me. All my work at art school was created from a space of finding meaning in suffering and seeing beauty in brokenness, so when Evie was born I had this sense of, "Of course it's her! Of course she would be the baby!" It felt like my whole life I'd been preparing for this devastating moment, and in that moment I felt complete happiness and freedom. So while it was a shock and it was hard and there was all this pain because the doctors didn't know what was going to happen, I loved her. And there was a beautiful tension in being so happy and so fearful of losing her. And she taught me so much about being a mother. She showed me parts of myself that only came out because of her.

"She taught me that motherhood is about being constantly broken and put back together a little bit stronger and braver, a more whole human."

And she lived to be two and a half?

She did. And over that time it was a rollercoaster of highs and lows, ambulance trips and learning so much from her. She never learnt how to eat food so she had this special formula and it made her breath smell like vanilla. I loved that [laughs]. She had so many amazing things about her and the way that she interacted with the world was just so beautiful. I started saying that she had superpowers because I believe she had electromagnetic sensitivity. When we drove under electrical pylons or went through electric sliding doors she'd cry every time. It was like a switch. So I imagined her as baby Magneto off X-Men! She was a person with disability and the world would see her as something less-than, but to me it just elevated her into something really incredible.

You saw her for everything she was.

Yeah, and you know, it was just exhausting always answering the "what's wrong with her" questions. I didn't want to focus on the list of medical conditions. So with this new language I started saying, "Actually, she has superpowers." And then they'd look at me funny and ask what I meant, and then I would tell them all the amazing things about her. Then in that moment they'd really get to know her, and she became a human to them rather than a collection of failing body parts. And after that they had a different view of disability as well. Because

"disability isn't a deficit within a person, it's a deficit in a culture that doesn't accept or enable a person for who they are."

Evie had such magnetism as a tiny human. I could see how she would draw people in, how her fragility and pure joy disarmed people and softened them, and encouraged them to see beyond her disability. She helped bring perspective and healing to people in very meaningful ways. And I had the sense that this was how she was choosing to do life. That she wasn't limited in her body. It just made her innovative [laughs]. Her limitations were actually her greatest strength because she was so determined to do the things that she wanted to do. She scooted on her back instead of walking. She communicated with us just with the tone of her voice and a little sound "ooh." I could feel what she was thinking or feeling and I knew she understood me. And she had this wicked giggle when we'd make her laugh and it was just so much fun. It was such an honour being her mum.

And so how has your life changed through all of this?

Oh man. It's made me braver and stronger. It's helped me to see a bigger version of humanity, and to see that chasing perfection is such a damaging lie. I've become more accepting of people, less afraid of them—especially those who are different to me. And I was just really proud of the mum that Evie allowed me to be. I was stronger than I thought. I called the ambulance so many times I lost count. We nearly lost her so many times and through it all I remained clear and calm. I stepped up and coped in extremely difficult situations. So even though it was hard and there were challenges, at the same time there was a lot of growth. I became innovative too. I found ways to communicate with her and play with her and advocate and fight for her.

"Evie showed us a completely different kind of love. Hers was a love without words."

I think also my heart was working overtime too. Through everything with Evie my marriage was suffering. All the love my husband and I had we directed to Evie and

through Evie. She was our connecting point. It was a painful love. Every day I'd wake up and rush to her room, "Is she alive? Is she alive?" And just constantly holding that in tension, I don't even know how to explain it. It's like being so vulnerable and open all at the same time. It hurts! Like even when you're in love, you know, you love so much it hurts. It's that same feeling. I think to be openhearted has more sharp edges than we think. It's not fluffy.

It's painful as you say. Although maybe pain is what helps us love more fully. If we actually acknowledge that this love could be lost maybe that's just a deepening.

I think so. And I think as a parent holding the knowledge that every day could be the last made love even more critical. I was really in the present. And after Evie died it took me ages, like years, to be able to think about and plan for the future. I'd almost forgotten that way of thinking. I'd been so in the moment with her.

So how was that period of losing Evie, and that grieving process for you?

On the night Evie died she had gone to stay with Mum. They got on so well—Evie and my mum. She was fantastic. She knew all about Evie's medical stuff and how to do all of her treatments. And I was with a friend for her birthday, and Sam was two hours away in Timaru. We were struggling with our own relationship and needed space from each other. It was all really hard. The next morning Sam called me and I said, "How are you?" I can remember this clearly. And he said, "I'm bad." I said, "What's happened?" He said, "Evie's dead." Just out of nowhere. Evie was in Christchurch and I was in Dunedin and Sam was in Timaru and our physical and emotional separation was so apparent. And my poor Mum. She found Evie in the morning and thought she must have suffocated somehow. She thought it was her fault. But when I saw Evie she looked so peaceful. As if she had chosen her time. I don't know what happened to her, we didn't want an autopsy.

But you asked about grief. I feel like there's a language of grief that people don't understand. No one knows what to say. When Evie was still alive—this is a story I have to tell—when she was alive, Sam and I went to a Coldplay concert and they played the song "Yellow." It was one of the last songs and there were these giant yellow balls falling from the roof. It was so great! And I was just a mess. I turned to Sam and tears were streaming down his face and I said, "Why are you crying?" He said, "Why are you crying?" [Laughs]. I said, "It reminds me of Evie!" And he said, "Me too." I think it was just that line, you know, "You're skin and bone turned into something beautiful." And she was so skinny. She had an extra pair of ribs and she was so long and... and so tiny and long and skinny and bony and she had these little stick legs! And I used to put her in stripy tights... she was so sweet. And I remember thinking this was her song. And then when it came to her funeral I didn't know what to wear. Nothing felt right. I wanted just to wear comfy clothes because I didn't... nothing felt good. And then I said, "I want to wear something yellow." And so my friend went out and bought me some yellow things. And we played "Yellow." And every day since then I've worn something yellow. For the last seven years now. It has become a way for people to connect with my experience—because they knew this about me. They could enter into my world of grief by sharing something yellow. They would say, "Rach, I was walking and I found a little yellow flower and I picked it for you and Evie."

What a beautiful open gesture.

It was magical. And people would leave me yellow jellybeans on my desk sometimes. And there's a friend who gave me daffodils every spring because he has a farm full of them. It's become this language that has allowed so many people to express their love and

sense of loss of Evie as well.

Because words can be hard.

Because they don't know what to say, and they don't want to say the wrong thing, but they want to express care.

And how was that time after her death for you?

It was shit. I went through a dark hideous phase of not wanting to live. Just that enormous absence of love. I didn't know how I would ever be okay.

Who was your support? What was getting you through?

Well I was writing in a journal a lot, and listening to a lot of Mumford and Sons. Their songs speak about love and loss in a way that just went right to my core. The experiences they sing about resonate so strongly and I found comfort in the lyrics. And I was talking to my friends and Sam. But at the same time Sam and I found it so hard to talk to each other because it was too painful. I'd look at him and I could see his pain and I couldn't hold mine and watch his. So it wasn't until about six years after Evie died that I finally felt the grieving process had come to a place of peace. That's when Sam and I took Evie's ashes to a very special place to us, Lake Pukaki under Aoraki, which is a mountain in New Zealand. And

"we scattered her ashes, and she became stardust and galaxies, she became part of the water and the sky all at once."

And in letting her go I actually felt joy. I didn't know what I'd feel, and thought that I'd be afraid to let her go fully. But there was just so much peace and overwhelming gratitude to her for teaching us so much and for being part of our lives.

It's such a profound story of learning and love between a parent and a child. Really a reminder of just how much young people have to teach us as adults about how to live fully. And so tell me how the Super Power Baby Project came about—because that's been huge for you.

Yeah, so one day while Evie was still alive I had this idea to travel around New Zealand and meet other children with chromosomal and genetic conditions and photograph them beautifully and discover what their unique superpowers were. I just thought, If I felt so much joy in being Evie's mum and in discovering her abilities, maybe there were other parents out there who felt the same way but didn't know how to communicate those feelings. Three years after she died, we started making this book. I'd never made a book before in my life but Sam and I were a great team and we worked it all out and did it really well. And I think in doing this project, that's when my real grief healing process began—meeting the families, sitting in their lounges talking with them, and just being part of that world again, it connected me to that way of parenting. It just threw me straight back into that world again, and just the way that I was able to communicate with their kids, it was exactly how I used to communicate with Evie. It felt so natural.

Tell me more about this way of communicating.

This way of communicating is really about intention. You don't use words, because you can't, you use your thoughts and you send love to the other person. And they feel it

through your body, your facial expressions, sound, touch. It's amazing! After Evie died, people with children were wary around me because they thought their children would make me miss Evie. But it wasn't the case because the experience I had with Evie was completely different to theirs. Other children just fascinated me because Evie was so different to them. But when I met the families with children like Evie, that was when I missed her—because I understood the parents, I knew the depth of their challenges and the joys of their triumphs. I spoke their language.

And that's actually a big part of the work you're doing now, sharing this language. I loved hearing about this form you created for the healthcare practitioners to highlight the potential in babies with medical conditions.

Oh yeah, Evie's Awesomeness form! That's been really cool actually. So at one point we were asked to fill out a "needs assessment form" by some of Evie's specialists. This form is actually positive—it asks questions about a child's abilities to gauge the level of support a family requires. And at the time, being exhausted and so used to medical stuff surrounding us, this form actually broke me. I couldn't tick a single answer to the questions they were asking about our child. So I had this feeling that when the people at the other end read this form, they would think from the answers I gave that Evie was a child who couldn't do anything and that she had no value. And while this might mean we would get a bit more medical or even financial support, it wasn't the most important thing to us. I wanted the people at the other end to know about Evie's abilities. I wanted to be asked about the things she could do. And I had become so exhausted by all the could-nots that I decided to make up my own form to go alongside the official one, with better questions. And I loved answering my own questions, because I could see how far Evie had come and how she was growing and developing in her own excellent style. So I guess looking back now, the motivation for making this form came from a place of wanting a better way of getting the information on how we might need some support. I wanted to share the humanity of my child. I talked to my OT and speech therapist, they were beautiful ladies, and I said, "I've made my own form, is that okay?" And they said "yes!" [Laughs]. And I said, "Can you send this one in with the official one too? I don't even care if no one reads it but I will get the sense that I've done something good!" And they did! So it's called "Evie's Awesomeness" with my questions on it with big yeses to every single question. And some of the questions are just super random—"Does she like it when soft objects fall on or near her face?" [Laughs]. Because she loved it! She loved it! [Laughs]. And every time I talk to health professionals now, I share the Evie's Awesomeness form. It's such a simple idea that clinicians are drawing inspiration from.

"I'm suggesting that health professionals add a paragraph about things that a child does that brings their family joy. "What does your child love?" or "What have you enjoyed about your child this week?" Then these beautiful things become part of the child's official medical report."

Actually, some health professionals are calling this section "the Awesomeness Report." Which is so cool! And both parents and professionals are seeing great progress when this attitude of ability and humanity is adopted.

Amazing. It's so amazing! And so I'd also really love to hear about some of the kindness you did experience in the healthcare system, I imagine you did amongst the difficult ones—how did that affect your experience?

Yeah, I remember we were in the Pediatric Intensive Care Unit in Starship Hospital in Auckland and we met this beautiful doctor, Lindy. She had such an impact on me. She got

Evie stable and then spent half an hour on the computer making her a pretty bedside poster with her name and a picture of a fairy on it. To make her bed less scary.

Oh how gorgeous!

Little moments like that are magical and completely unexpected and just something that changed my whole perception of what healthcare could be. And I still have that piece of paper now. It means so much to me, she was so particular about it. And she didn't rush it—she wanted it to be perfect. It was like this little poster was just as important as everything else she was doing for Evie.

So I guess to circle back to where we started, in response to all my experiences with Evie in the healthcare system, I've been thinking about the impact of language and communication quite seriously. And I'm part of the Thought Leadership Business School here in Australia which is helping me develop my ideas around how communication style can destroy or build the relationship between a health professional and a parent or patient. I developed a language matrix that came from me thinking deeply about where language fits. And my favourite health professionals were the ones like Lindy that communicated in an openhearted way. They were warm and positive, they spoke to me in a way that made me feel important and that the things I knew about Evie were really valuable too. And their approach was not only best for me and best for Evie, it was also best for them as health professionals because I wasn't relying so much on them. You know, they taught me new skills so I could do more for Evie at home. There was respect and trust and I was empowered as a mother.

"I think the relationships between medical staff and parent or patient are often being severed by thoughtless words, and that's such a tragedy because the knowledge of the professional isn't being utilised. And the knowledge of the parents isn't being respected."

And it's so simple and easy to change, which is the beauty of what I'm teaching.

But does the system have to change as well? I mean I know you're not a health practitioner. But what have you noticed as to why communication isn't as effective as it could be? Doctors have all these great skills, this great knowledge and intellect, why does the empathy and the compassion seem to be absent? And obviously this isn't the case for all. But what are your thoughts?

Well from what I know, it's not taught well from the beginning. And if people had it when they got into the medical system, it's almost trained out of them. The system is really set up for 10-minute interviews. People say there's no time to be compassionate, they've just got to give the facts, the diagnosis, the medication, get people in and out. So there's an emphasis on the disease rather than the human, and to be honest I think professionals hate this as well—because they want to care. They want to help people and have better relationships with parents and patients. And they're limited by the system too. So they're burning out because they're seeing too many patients at not enough depth. Maybe they feel like they're being ineffective. There are actually so many studies and statistics about the fear of failure from health professionals. We're all humans and I feel like we forget that when we walk into a hospital. I know that when I let go of the expectation that the doctors should know everything, I let them be human. I was kinder towards them and myself, and I learned to respect what they knew and the things they didn't know. I think what is also often missing in the healthcare system is a sense of true hospitality. Hospital and hospitality come from the same Latin root word, *hospes*—which means guest or stranger, and carries with it a story of mutual respect between guest and host. An

expectation of all parties to exhibit care, trust and kindness. So the etymology of the whole system is actually based on a beautifully kind and compassionate foundation. But I don't actually think compassion is missing in healthcare, it is just often misunderstood—by patient and carer. When we can build a healthcare system that can look after everybody under the hospital roof, then we will have something pretty incredible.

Given you're an artist yourself, I wonder what are your thoughts on the role arts can play in building a better healthcare system? What is the relationship between the two?

It's pretty exciting actually, seeing how my art brain is connecting to this deep thinking I have around systems and change. I am able to build models by using art, story and metaphor as a way to communicate solutions to complex problems, which is really cool. The way I see it, a hospital is a place where all the vicissitudes of life reside. All the shifts and turns and highs and lows, all the seasons of life—and they all deserve care. And the best way to care for a person is to respect them. Art helps us do this, it has a way of transcending language itself—instantly connecting us as sensory beings. It reveals messages and meaning, it can create comfort through a colour palette, a chord, a poem, a photograph. Art can enhance an environment or soften it. It creates space, it allows room to breathe and connect to the present.

"I think art helps us acknowledge our own humanity, and remind us that we are all in this together, all deserving of the kindness of strangers."

Which is why the Super Power Baby Project has had such an impact I guess. The images in the book shine back at you with so much life! Photography was my tool for communicating how amazing the children are. I was able to capture them, and their personalities and spark in a way that connects with people in a really deep way. I actually show a slideshow of the images from the book at some of the talks I give, and health professionals are in tears because the images speak so much of meaningful life and love. It's almost like they are reminded of a language they forgot, like they are reminded of why they became doctors in the first place.