



Chapter One: 'We were broken but we didn't show it': Grieving in anticipation of my child dying

Featuring Yvonne, Angela, Rachel, Bec

Unmasking Grief Series

Q. How would you describe your experience of grieving before your child died? (00:10)

Bec:

We had this beautiful, healthy baby boy. We were in this bubble for the first five-and-a-half months of his life of newborn bliss. We had our little family of three and it was everything we had dreamt our family would be. Then the day came where we received the diagnosis that our beautiful baby boy had a life-limiting condition.

Rachel:

In the beginning, you grieve the potential loss. It's like a compounded grief. Like Evie's still alive but again, she was also given a life-limiting diagnosis and so then there's the fear of loss while you're holding onto a life.

Bec:

Throughout the journey, every stage, every additional diagnosis, every change, every deterioration, progression. Every time that - what the new new had become changed again, we grieved again and we - it really was a rollercoaster ride.

Yvonne:

When your grief journey begins, it is diagnosis day or when you show up at the paediatrician and they send you for tests.

Angela:

I just felt like we were in survival mode and just the extreme pressure of trying to savour every moment just watching her breathe thinking soon I'll never get to see this happen again. But trying to be happy. So trying to protect her from our sadness. So you know, singing her happy Rosie Rosa songs and yeah, trying to shield her from the devastation we were going through knowing that she was going. I guess as parents, yeah, you kind of try and protect your child.

Rachel:

I also remember, we were given gifts by friends and family. I remember feeling really sad because we were given a book and it brought me so much pain because I realised Evie might never read this or she might never wear the clothes that she's been given. She might never play with the toys that she's been gifted. So there's - yeah, there's that compounding grief of the unexpected and the unknown.



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Angela:

Yeah, well you have no idea what you're doing, do you? You don't know how to parent a child who's going to live when they're your first child and we weren't expecting her to die. Like it wasn't till after she was born that we were told she was going to die. Yeah, you're learning all that - all the new stuff about parenting and then sort of the paradox. Like I just didn't understand, yeah, I could see her growing and I thought, well how can you be growing if you're dying?

I noticed her eyelashes getting longer and she was achieving developmental milestones but she's dying. I just didn't understand that. Yeah, how someone could be flourishing while they're dying.

Yvonne:

The grief journey starts with that room of specialists, health professionals and that box of tissues sitting on the table. For me, that's such a - and our family, is such a vivid, vivid memory. Boxes of tissues are a grief journey for us because that box of tissues is forever present in the grief journey.

Angela:

It's like this cruel gift. You're given this - you know, the most precious gift in the world that's beyond anything you ever thought as being wonderful and you're like, well why give this gift and then kill it?

[Laughs] You know? Why is this beauty flourishing only to suffer an extreme way?

Q. What other losses did you experience throughout this time? (04:27)**Yvonne:**

Firstly, I had to resign from my job. I was actually told that I'd affect the children I worked with. So I was asked to resign and that - so that was a loss of income then. Because our daughter's treatment was in Sydney, we were separated so I sort of - I lost my family for 12 months as well. They couldn't visit because of being isolated and they had to - someone had to earn money and my older children had to - we have a normal life as possible that they could too because they were older and had their studies.

Rachel:

I just remember losing all sense of peace and carefreeness. You know, just even moments of joy with Evie was tainted with pain so even joy was diminished. Yeah, it's an all-consuming thing, grief.

Bec:

We had to just roll with it and roll with the punches but I feel like along the way, I lost bits of me and who I may have been as a person or as a mother. I lost a lot of my younger son's childhood that I don't - I don't remember bits of it because - and it breaks my heart to even admit that.

Yvonne:

We also lost our home. We owned our own home and we had to sell it to pay for things so that sense of losing your family home too. It was another thing that was so difficult so - and I feel that you lose your relationship with your partner, too, for that period of time.

Rachel:

The losses kind of creep up on you a bit and you realise you've lost friends or you've lost a way to communicate easily. There's a loss of ease and peace.

Bec:

I was so focussed on caring for Marc and caring for Anthony too but with all the hats we wear, I lost the opportunity to just wear the hat of being mum.

Yvonne:

You lose friends because some people won't understand what you're going through and they don't want to be part of that journey because it's too difficult for them. So there's so many losses within that experience of that time.

Q. How can healthcare professionals avoid causing unnecessary pain? (07:23)**Angela:**

Some of the things that weren't helpful were [laughs] like an expert from the Children's Hospital at the time asking why we were still feeding her. Saying, look, she's going to die anyway, what are you bothering feeding her for? I was just quite aghast at that. I was like, well she's seeking food. She seems happy when we give her food. We weren't giving her usual amounts.

Rachel:

I think healthcare professionals hold a lot of weight in the amount of care they can provide in the very first moments when they're giving a diagnosis, especially. It's all around the language that they use. I just remember the words they used to tell us about Evie's condition were so dehumanising. Like they didn't really even describe a human being. They used words like congenital defects, skeletal abnormalities. You know, incompatible with life. That she'd be retarded. The diagnosis words around Evie didn't even feel like they described a human being.

Angela:

My despair in the hospital, so when we were told she was going to die, obviously I was very upset and I was crying quite loudly. I could hear staff say, could you get her to quieten down? She's upsetting the other parents.

Rachel:

I could see that she was a beautiful soul, full of potential and that she was alive. There was life. I understand that they have to give the technical, scientific, actual diagnosis but if it was delivered in a way that was understood, that had more compassion, that explained some of the big words. Because you're learning a whole new language in the midst of being terrified and confused and afraid. So you can't absorb the information that they're sharing.

Angela:

To be on the ward where all the other parents - we'd just been told she was going to die and there's - all the other parents rooms have got relatives celebrating with balloons and lots of woo-hooing. It just seemed not right, you know?

Rachel:

If healthcare professionals could really understand the emotional impact and the emotional landscape the family are going through when they receive a diagnosis, maybe they would look out for them more.

Bec:

Having health professionals around you who understand that and are sympathetic to how much impact this journey has on parents and families and children and the child themselves, is so important.

Angela:

We didn't want her to die in hospital. So on a day when I thought she didn't particularly look quite good, so we were there for 10 days, I said, look, I want to take her home. They said, well you can't take her home. I said, well could you please call the doctor? Then they said, call him yourself [laughs]. They just said, you can't take her home. So it was great to have an advocate in the paediatrician. You know, he liaised with the head of the hospital and said if anyone tries and stops you from taking her out, then ask them to talk to me.

Rachel:

I remember we were in a hospital. It was a teaching hospital and we were constantly faced with a lot of fresh-faced students. So every time we were in hospital with Evie, these students would then get to practice on us, you know? Asking a lot of questions. Because Evie was so rare, it was an opportunity for them to really learn and so we had to keep retelling the story over and over again.

When you're in that enough, it is just completely exhausting and overwhelming. So healthcare professionals, I think, have a duty of care to look after the emotional wellbeing of the parents they're looking after. Especially when families are being asked to also serve the teaching community.

Angela:

So when I came into the paediatrician for a check-up and I'd say, you know, do you think it's okay what we're doing? I think I was just still conscious of the messaging I got from the hospital that it was not okay to take your child home. I was like, well it feels okay to me. Rosa's responding. She's quite thriving, actually. She ended up living a lot longer than you said she would. So he'd make comments like, well she's living the life of Larry as far as babies are going. She's not here for a long time, she's here for a good time. That just resonated that yeah, we're going to have a fun time with Rosa and make her feel our love.

Yvonne:

I think they really need to also think about the child too because often, when it's an older child - speaking from our - from the perspective we had, rather than talking about them, like they're not there, include them within it as well and also - so it's being inclusive. Being empathetic and speaking the language that they'll understand too, that's gentle - delivers it gently but so they can process it as well. I think that's really, really important.

Bec:

Some of the - I don't know best interactions is the best way to word it but some of the interactions with health professionals that left us feeling supported were where they came into the room or came into talk to us and the first thing they did was talk to Marc. Acknowledged Marc and say, hey buddy, how are you doing? Talked to him and us and to Anthony. That was - that connection was made and it was so important. It meant so much to all of us.

Yvonne:

When there's siblings, too, the older siblings, they shouldn't be shut out either by the healthcare professionals. They should be embraced and involved just as much as the parents are.

Angela:

Our GP, she had some really frank discussions like, have you thought about where you want to be when Rosa dies? I'd said, oh, well I thought she could die in our bed but I didn't want to then feel funny being in that bed thinking, oh, this is the place she died. But she helped normalise that and I think she said that Rosa's living a life of love and not many people can say that. You know? Rosa's going to have lived a full life filled with people caring about her and loving her. There's not many humans who can say that. So it just felt - I don't know, just that valuing her life and honouring what we were trying to do.

Q. How did you balance grieving in anticipation of your child's death and embracing life and living? (14:45)**Bec:**

We didn't know how to do that in the early days but we learnt as we went along the way. Marc was our beautiful blue-eyed hero and he showed us how to live. He taught us how to live.

Rachel:

Initially it was really hard to embrace life with Evie as well as anticipate this potential loss. I learned a lot from Evie, actually. She taught me how to live in the moment. She taught me true presence and that was a powerful thing to the point where after she died, I found it hard to think about the future. It's almost like I just stopped thinking about the future which allowed me to stay really close by and present.

Yvonne:

She was my guiding light. She guided us to live. To live with her in the time she had and to live within quality love. Joy. Adventure. Giving and just it was her. She guided us and we just went with that flow.

Angela:

But I think with a child, yeah, you're conscious of trying to be fun. Justin - my husband and Rosa's dad, he was super silly and [laughs], I think he - on his nightshifts, they'd watch It's a Knockout and he'd always talk about athletes as being over-achievers. He's not particularly into sport so you know, just chat to Rosa about silly things and - like a normal dad would. Yeah.

Yvonne:

We were all grieving, we knew what was going to happen but we were making memories. Making moments. Making those things to treasure, guided by her and her choices and her wishes.

Angela:

Something that I enjoy doing with Rosa is - because it was quite cold when she was dying, it was winter and we went outside and stood under these really large palm trees - ah, pine trees. They were really large and I said - and it would be night-time and it was cold. I'd say to Rosa, can you hear the wind blowing in the trees? I'd have her little cheek up against mine and then I'd say, Rosa, can you hear the birds? They're saying - they're talking to you. They're saying, we're glad to see you [laughs].

Bec:

Somehow, no matter what he went through, what happened, what the day held for him, he always just loved life and loved everything and everyone around him.

Angela:

I remember thinking, you know, I'm going to stand in this spot soon and I won't feel her warmth against my cheek. I won't smell her smell but I'll still hear the same sounds but she just won't be with me [cries].

Bec:

He loved to lay out in our garden under the trees and look up through branches and see the light dancing through. From those very early days, he taught us that and it's a lesson we carry with us to this day that no matter how many shadows there are, you can always look up and find the light sparkling through. For us, we carried that with us his entire journey [laughs],

Angela:

The neighbours probably wondered what I was doing but I used to spend long periods of time just [cries] standing under those trees.

Bec

We made memories and we went on adventures and we went and just sat out under the trees and lazed the day away looking up at the branches and sunshine and it just really - he really showed us what is important in life.

Angela:

I think whilst she was alive, there were lots of little things I did that I knew would help anchor me when she wasn't there. Like I bought her a little bracelet and I called it her bling [laughs]. She liked showing off her bling and she had it with her in the morgue. Then I took it off her before the last time we saw her and I just carry that with me. My shirt. Like when I went to work.

Rachel:

I wrote little notes to her. I had a little notepad by her bed and I'd write little things that happened during the day or things that she did or new things just to kind of help me remember or to ground me in the moments of the day. I took a lot of photos of her. I took a lot of videos. Just to - yeah, keep me fully in the present space.

Angela:

But there was - I guess also periods of feeling really selfish because there was a time when I thought - I was having a shower and Justin called out. It looked like Rosa had died and I'd missed it. That's the thing, like you didn't even want to go to the toilet because you wanted to be there. I rushed out of the shower and I kind of shook her. You know, she was all limp. I was like, Rosa? You know, I just want one more walk around the garden. [Cries]. Yeah, so I just kind of - then she came back to life, you know? She had this big inhalation and while I'm holding her saying, please, Rosa, I just want one more walk [cries].

Bec:

It was tough at times. It was tough many times and carrying that grief, knowing that at some stage we would lose our little boy, that was hard but we had the greatest joy of having him in our lives and showing us that living is important.

Angela:

[Cries] Yeah, Justin - we don't talk much about our grief but I think there's a kind of a real grace in someone witnessing you through that. He said, you know, it's best for her if she goes. She's lived life longer than she's supposed to have. Because she was struggling towards the end with seizures and stuff. Then immediately [laughs], when she came back to life, I kept apologising saying I'm really sorry [laughs]. You know, don't worry about me, don't worry about us, we'll be okay [cries]. Yeah, then her breathing became quite tricky. That was sort of the beginning of the - you know, the real obvious end. But I - yeah. Yeah, as I said, Justin and I don't talk about it much but I never forget that kind of - [laughs] him trying to support me and also do what was best for Rosa.

**Q. What did you learn throughout this time that you would like to share with others?
(22:49)**

Yvonne:

So what I learnt throughout this time that I'd like to share with others is that really live each day as it unfolds. Provide love, provide opportunities. Have your family close and create those special moments because that's something you'll treasure always.

Rachel:

I guess I learned the value of a human life. That no matter how long or short it is, that they have significant impact and that each life changes the world because they have been loved and yeah, a short life doesn't mean that it has a less impact or less value.

Bec:

If someone had told me earlier on in our journey to not sweat the little things, to be in the moment, to lay out under the trees and just live and make memories and know that it all means so much and it all - even just the littlest moment that at the time you may not realise is such a significant moment in your life, later on you will carry that moment with you for the rest of your life.

Angela:

I guess what I'd like the world to know is that if someone's going through a tricky time, that just being present and just sitting alongside meant all the world to me. There's no pressure for you to fix the situation.

Bec:

Think about today. Remember yesterday in your heart and know that tomorrow, the impact that your beautiful child made and the love that they shared and the love that you have for them will exist forever.

Angela:

As the person going through it, I think what I would say to myself is to be more gentle. Be more gentle in my expectations of others. Be more gentle in my expectations of myself. That it's okay to be sad and be happy at the same time.

End

Reading these stories and confronting suffering may not be easy. When feeling vulnerable, some people find it helpful to lean into the comfort of trusted family and friends, a family doctor or counsellor. If you are seeking urgent support we encourage you to contact Lifeline on 13 11 14.