



Chapter Three: Waking up to the 'angry raging monster' of grief: grieving beyond the death of my child

Featuring Yvonne, Angela, Rachel, Bec

Unmasking Grief Series

Q. How did you make the transition from being a full-time carer to becoming a bereaved parent? (00:10)

Yvonne:

Making the transition from being a full-time carer to being a bereaved parent, wow. Do you, really? I think you still always feel like you're a carer, or have to care. It's like it's programmed into you after you've had to do it for so long. Yeah, so what is the transition? What do you go to after that? You're a bereaved parent.

Bec:

I remember my husband and I sitting on the couch, and I just remember not being able to cry anymore and just feeling like a shell. We just felt like shells sitting there, and just everyone's lives had started again. Everyone had gone back to work. Everyone's worlds just were spinning again, and ours stopped at the moment Marc took his last breath.

Yvonne:

There's widows and widowers, and bereaved parents don't get a title. We're not really recognised like other people are in society that have those terms. So I feel like you're very forgotten and lost within the community, so how do you move on? So if you go to look for work, it becomes - well, what were you doing for that break in time? You say you were a carer, and they go, but you haven't had current experience. So you get all these knock-backs and that kind of makes you feel like you're not good enough, as well, like you're not worthy of anything then?

Bec:

It just was this feeling of what do we do now? How do we keep going? We have to keep going for Anthony. He needs us, but how do we do life now?

Rachel:

Yeah, I found the transition incredibly difficult from, well, being a mother of a physically alive in the world child. I don't know if I identify with the word carer so much. Evie was only two and a half when she passed away, and she was on medical equipment, but she was pretty strong and healthy when she died. It was a complete shock. But a real challenge I found was - and the months after she died - was giving back all of the equipment that we'd had from the hospital and from the support people. It's almost like it was a re-traumatisation of having to give things away, and it was like another piece of death, or another grief.

Angela:

I think I just was just sitting there, looking at the birds for months, just sitting in the garden and watching a baby bird learn to walk along the branch. I'd talk to Rosa, saying, oh look, Rosa, this bird's learning to walk. I think just watching leaves unfurl and flowers unfurl, and just talking with Rosa and going for bushwalks.

Rachel:

I remember having to go to the hospital to give this equipment back, and I wish someone else had done that for me, because every time I went back to the hospital for any little check-ups, I couldn't walk in the doors. It was like there was a PTSD response from my body, and I couldn't do it. It took a long time to heal that memory, and so the transition actually takes longer when you've got to deal with these unexpected grief triggers that you just don't think about. So transition can be a really difficult, unexpected challenge.

Angela:

I used to really struggle with - I just - I was still a mum. I felt like, right, I'm still a mum. I just don't have a physical baby here and a physical child, so I thought what can do to still be a mum? So maybe that's how I processed my grief, was just trying to be creative, so I had this little - it was a heart-shaped bell, and I'd carried in my pocket, so when I went bushwalking, I'd think, well, every step I'm walking, you're coming with me, Rosa, on this journey. I wanted to let her know that I wasn't leaving her behind.

Rachel:

As well as just having to adjust to life without your child, there's these other layers, so maybe there's something that support workers and the team can help to pick up on and carry that load for the parents.

Angela:

That period after she died, I just remember the resounding silence, as well, that you've gone from one extreme of being very busy, not only caring for a child - and a living child takes a lot of caring. Then the extra requirements of a dying child, and then that all stops. I think people think, ah, they're having a tough time. I'll just give them some time to themselves. Whereas when she was alive, there's lots of phone calls, check-ins, how's she going? It was just a lot like - silence has a sound, a deafening sound.

Yvonne:

For me, my where to has been keeping Dainere's memory and legacy alive. She did so much work to elevate awareness and raise funds of the disease, brain cancer, that she died from, that - and she left diaries and notebooks of ideas for us to continue her work. So obviously, that was my go to then, so it's like carrying her along as a bereaved parent to continue doing what she did and something there for me. So yeah, I do all that work, but that's voluntary work, so - and I love it to bits. But it doesn't pay bills, either.

Angela:

I'd stand and look at the living room where we lived a lot of Rosa's life, reading books on the floor together, or I'd do my exercises, and she'd lie on the rug next to me while I was teaching her about my exercises. I'd just look around the room, and all her toys were there, but she wasn't there, and...

Yvonne:

As the carer, you know what to do and you know what you've got to do at a certain time when you're giving medications, when you're giving - got to go to appointments. You've got a bath or you've got a whatever you have to do. But as a bereaved parent, you're going, what do I do now? You actually don't really know what you've got to do, and I think I feel like I always think of that transition thing as it's a puzzle, and you're trying to put the puzzle together, but there's always a piece missing from that puzzle. So you actually can never complete the puzzle.

That puzzle piece that's missing is your child, your life, that it was before, during and then after. You can't find that puzzle piece. It's forever missing.

Q. Can you share some of the feelings and emotions you experienced after your child died? (08:50)**Rachel:**

The emotions and experiences after Evie died are just - I just remember waves of pain, and I remember, Yvonne, you mentioned you just want to go with them when they died. I remember, when Evie was being lowered into the ground, I just wanted to jump in as well. I wanted to die, essentially. I didn't want to live anymore.

Angela:

Well, I think before she died, I was worried that I might want to end my own life when she died.

Rachel:

I had to be really careful with myself.

Angela:

That period passed quite quickly for me, and maybe because I thought - like Rosa didn't get to live her life, and I'm not helping her by not living my life, either.

Rachel:

It was just true suffering, pure anguish, and I felt a despair like I'd never laugh again, or I couldn't even remember feeling what it felt like to be happy or to feel joy. I didn't know if I'd ever feel those things again, because I couldn't remember ever feeling them.

Yvonne:

You're angry at yourself a bit, because you feel like you could have done more. You're angry at people around you, because perhaps you - they didn't support you enough or they say the wrong thing, or you see them doing something, and you're angry, because why are they doing that, and I can't?

Rachel:

Yeah, it's like waking up just to a darkness. I don't know even how I got through it, really, because I kept working, and I think it was just - I was determined just to make it through a second at a time, a minute at a time, and then a day at a time. I just had to stay in the very present moment.

Yvonne:

Then you feel anxiety. I can use an example of that. I remember it was a couple of weeks after Dainere died, and I thought, I'll go down to the shops to get some milk. I walked down there, and I got to the shop, and I got in there. It seemed so busy and noisy, and people around, and there were mothers with their children. I just froze, and I got really shaky and really frightened, and I remember running out of the shop and finding a little corner. I rang my husband, and I said to him, you've got - can you come down here? I'm scared. I'm too scared to be out.

Rachel:

I remember not being able to make decisions easily. I'd keep backflipping, like I didn't know even what I needed or wanted. It's like I couldn't decide anything, because nothing felt right at all. I remember people would tell me, it'll just take time. You just need time. I couldn't - I hated when people said that, because I couldn't imagine time long enough to heal this depth of pain that I was experiencing. But I remember just feeling that I had to just trust that one day, it would be different.

Yvonne:

You cry a lot, and sometimes you cry so much you have no more tears to cry. I found the shower was the place that you'd often cry, and I know a lot of mums have said this. As the water's falling in the shower, so can your tears, because you're also - you don't always want to show other people that you're crying, so that shower becomes a safe haven for you to cry.

Bec:

In the early days, there was just so much numbness. I just remember feeling like I could walk through a fire or stand in the snow and nothing would - I wouldn't be able to feel anything. I was just numb to my core, but I was angry and sad, and resentful and didn't know how do I keep going? But I have to keep going for Anthony, but I just want to be with Marc at the same time, but I can't, because I've got to be there for Anthony, for my husband. It was hard to cry, and I - like Yvonne shared, shower was one of the places that I could cry.

Yvonne:

Another feeling is you feel lost. You just don't know what to do, where to go, how to react. Yeah, and you feel - you're living with uncertainty every day.

Rachel:

But at the same time, I was this fully functional person who kept working, and I don't know how that could be. I was angry that I couldn't stop. I really wanted to be able to just stop and grieve, and there was so much pressure to keep going, to stay strong, and financially we needed to keep going. Yvonne, you've mentioned, you lose your job, you lose your home, you lose your relationship, you lose so much. So the only option I had was to keep going, because everything is at risk, and so I was angry at everybody around me for not seeing how broken we were and for supporting more. Yeah.

Q. What is it like to be grieving as a couple? (14:29)**Angela:**

Look, grieving as a mum and dad, just after your child's died, I know - I'm curious, if any couples get gold stars for navigating that period.

Rachel:

That internal angst and anguish can do a lot of damage, especially with dealing with my own grief and then watching my husband go through his. I couldn't hold his and mine at the same time, so I remember rejecting him if he needed a hug or needed support. I couldn't. I know that there was damage done in our relationship because of that, this depth and this rage and this anger. It came out as unrecognisable emotions and feelings. I became somebody that I didn't know.

Angela:

Because I don't think you're going to chat to each other going, right, this is how I'm going to fall apart, and how are you going to fall apart? Because the way you fall apart's quite different. We had - we still had oxygen at our house, and morphine and I could hear Justin downstairs, inhaling some of the oxygen, and I didn't know if he really wanted to be alive after she died. So I thought, I'm not just losing my daughter. I'm losing my husband, and feeling lonely, because they're not there for you. I wasn't - I couldn't really be there for them either, for him.

Rachel:

Rage was a powerful one. I'd never experienced rage before, or just a deep - I think it was just such a deep grief that the closest expression that I could get rid of it was anger, and rage, but it was an internal rage. I wasn't violent or I wasn't externally angry. I just felt this despair, rage within me.

Angela:

It might have been someone from the pall care team just saying that people do things differently. I think that helped me to go, right - well, just to be respectful, I think, and not to be too hard on each other. But that's a devastating period, as well, because you've done the dance with death, and death has kind of won, and death isn't this airy fairy concept. Death is real, and so there's no reason why your other loved ones may not die.

Q. What did it feel like on your darkest days and how did you keep yourself safe? (17:17)**Rachel:**

It was hard to keep myself safe in the really dark days. I wish I had really forced myself to see somebody, see a professional, see a counsellor. But it was almost like it was - I wasn't allowed, or it didn't - I don't even know why I didn't get help, but I needed help. I did go to a GP. I was significantly depressed and scared for my safety. I was prescribed an antidepressant that my family discouraged me from taking it.

Bec:

Some of the dark days this year have been around me realising that I know this is never going to get easier, because we loved him so much. I can't imagine it getting easier, and I don't want it to get easier, because then it means I'm okay without him here, and it's a really challenging concept as a mum to try and process that it could be okay without him here, because it's not. It never, never will be.

Rachel:

It's difficult to talk about, because my beliefs about what I needed and my husband's beliefs were very different in this space, and so I didn't feel supported to look after myself from what I needed. So that was a real challenge, and it one was one of the things that I think as couples when you go through something so significant, like keeping each other safe is really challenging when you have different views on what's acceptable as a form of support.

Bec:

I think it is a process of accepting that you are still going to have hard days, and there's a lot more hard days than good. It's actually - there's very - it can feel like there's very few good moments even in those early days, the first year, the first couple of years. It's hard to even sit in the good moments comfortably, when you carry all of the grief and the loss and all of the emotions that you carry on a daily basis, being a bereaved parent.

Rachel:

I wish I had stood up for myself, supported myself. I think it would have done a lot of good. In the end, I didn't actually seek counselling until many, many years later, like 10 years later.

Bec:

I've had to find a way to accept that they can exist parallel to one another, that I will carry this with me always. I will have and continue to have days that are dark, where I can't function and I don't really want to function. But I somehow find a way to function at a level so that I can be Anthony's mum and be what he needs me to be.

Rachel:

Yeah, so it took a long time to process, but I was able to tell people when I knew that I wasn't okay, and I was significantly feeling like I was a danger to myself. I really did want to die a lot of the days. I felt like there was a veil, such a thin veil, between the world that I was in, this physical world, and the world that Evie was in. It was just so thin, and I could go there instantly, and so I had to really stay in this physical world. I had to force myself a lot of the time, but being able to say, I'm not safe, was everything.

Bec:

There are days where I am functioning, I am having moments of happiness and joy and good times, but I carry that whole, that missing puzzle piece that Yvonne shared earlier, with me always. There's always going to be a tint of sadness to any moment in my life because of that - and accepting that that's okay.

Q. How did others around you react? What was helpful or unhelpful? (22:08)

Angela:

Little things like receiving flowers for the funeral. I just was so upset about getting flowers, because I normally love flowers, and here is this thing of beauty, and flowers are - they don't have a long life. They're relatively new to the world themselves, so to watch them slowly decay, I just thought - I just found that difficult, and that's probably not something I would have thought of beforehand.

Yvonne:

People are around you when you're a bereaved parent and you're grieving, they all act differently. So some will act quite negatively, if that's the word you could use, where they just want to avoid you, because they just don't want to talk to you, because you might bring up your child and make them feel really, really uncomfortable.

Rachel:

I remember, I used to get asked a lot from strangers who didn't know about Evie, so, do you have children? The question, do you have kids? Then, what do you say? I remember initially I would say, no, and I hated saying no, because then I didn't want to deny my experience with Evie.

Yvonne:

You might message them, and they don't return your messages, or you'll see them out somewhere, and they'll actually step away, saying, please don't see me. I don't want to talk to you, so that's really difficult, and it's a - I can understand their point of view, because they just simply don't know what to say or how to react, so they're protecting themselves, as well as they probably think they're protecting you, too.

Rachel:

So I started saying, yes, yes, I have kids, and then they'd ask me more questions about my kids, and then I'd end up at the point where - then I would get to the point where I had to say, well, actually, she died. Then I'd have to protect them and backtrack, and it's not your fault. I hated when people asked me, do I have kids, and then how old are they and what school do they go to and blah, blah, blah. It's just - it's really challenging, and so I've almost had to make a script for myself now that I completely can control, and that if somebody asks me, if it's uncomfortable for them, it's going to have to be uncomfortable for them, that I need to look after myself in that space.

Yvonne:

Others will be ultra-supportive, like so in that way, they'll support you and tell you what to - oh, why don't you do this? Why don't you do that? Shouldn't you be moving on now? Don't forget, you've got other children, so Dainere doesn't matter anymore, because you've got these other children. To them, that's supporting you.

Rachel:

It took me a long time to really know what to say, because people are genuinely curious, and it's not an unreasonable question, but at the same time, people don't even really care. It's just a throwaway question, and they don't realise the impact that it's going to have.

Angela:

I don't want to be too hard on people, because I'm not sure I'd be any different. I'm just aware that people did stop calling me, to give me space. But that was probably when I was at my most fragile. After she died, I was at my most fragile and probably in most need of support.

Yvonne:

But then you'll have that in-between people, and they're the most important people of all. They know when you might need them, when to reach out and just listen or to just talk to you or to just simply give you a hug. They're the people that are healthy for you and keep you going, and they're true friends. That's what I found with those around me. Your true friends and true - and your family, often, are the ones that'll be there knowing what to do and when it's right and when it's not right, when to give you space and when to - yeah, be there, even if it's not even saying anything.

Angela:

There was a friend one day who did ring me, and she checked in and said, how is it going? I don't know if I was honest, but I started crying on the phone, and she said, I'm coming over. I said, no, no, I'm okay, because I didn't want someone to see me fall apart, and she came over and she just sat next to me on the couch. She didn't say anything, and she just - and I think that's one of the most helpful things, and because she didn't try to fix me. She didn't try to minimise what I was going through. She didn't try to distract me, and she really just bore witness to the pain I was going through. I think that's a really hard thing maybe for humans to do, is to be present with other people's pain and not trying to escape, themselves, or try and make it less than it is.

Bec:

There's your core people who are there for you and will pick you up off the ground and help you to do the most very basic of functions, who will sit with you and say no words and who are just there. They see you, and they see your pain, and they also see the love you had for your child. They see your child, and they talk about your child, and they say your child's name. That means the world.

Angela:

I don't think I've ever thanked that person for that over the years. I keep meaning to. She probably has forgotten that, but yeah, that was really helpful. For myself, there are times in my own life now when I see other people go through difficult things. I try to do that, is just to be present.

Bec:

Those people who are with you, and they're in the thick of it with you, they shine through, and they have your back, and they look after you, and they care for you. They still hold your child in their hearts, and at the forefront, and your child lives on through them as well.

**Q. What do you wish you understood about grief that you would like to share with others?
(29:25)**

Rachel:

Grief is an interesting one, because it's not linear, and people expect it to be linear. Once the funeral's done, they expect you to be okay, almost, and then once the first milestones, they think, okay, now, get on with it. You've had your time, and so grief doesn't have that linear shape. It's like a loop-de-loopy circle-y thing.

Yvonne:

Yeah, something I'd like to share with others about the early days and grief is that everyone actually grieves differently. For people to have acceptance of how everyone grieves in their own way and not to place expectations on how you should or shouldn't grieve.

Rachel:

It's been 12 years now since Evie has died, and so I feel even - I feel strange even talking about my grief, because I feel like there's almost a use-by date on when you're allowed to talk about it and when that's okay to - or when you're allowed to be over it. It's like, okay, we're done with you talking about your grief now. Shouldn't you be done with that? So it feels really tricky to be able to speak openly about grief years and years and years and years later, because it changes you completely. There is no use-by date on grief.

Angela:

In terms of understanding grief, I could probably share something I found helpful for my grief, was I would go swimming in the swimming pool, the local public pool, and I think I just liked the caressing of warm water, and I imagined it was Rosa caressing me. The thing I liked the most was that you can scream in water, because I just needed to scream at the world.

Rachel:

The shape of it changes, yes. It doesn't ever fix. It doesn't ever magically become all good, but the way that it sits in your body and in your spirit, it does change. So now, when I think about Evie, I think about her with joy, and with gratitude and with love, and so that deep angst, that rage, that depression, that monster is gone. It is gone, and I remember feeling when that significant deep grief left me, and I felt it turn into a sadness. Then, I felt it turn into appreciation.

Angela:

You can scream in water, and you lose your breath quite quickly, but you come up, and you just scream again. It was odd. People are just doing their laps next to me, and here I am, just screaming. I had multiple sessions doing that, and I don't know if anyone finds that helpful, but if you have a desire to hit something, that was my way of just physically expressing what was going through my body.

Rachel:

I always had a deep belief that there is beauty in brokenness. It's been a theme that followed me around my whole life, and when we finally did scatter Evie's ashes, six years after she died, we took some photographs, and I think again, we've all mentioned the power of photography or capturing moments or capturing pieces of time. My most favourite photograph is me standing in turquoise waters, scattering Evie's ashes, and to me, it's just a celebration of who she was as a person and the utter gratitude that I have for the things that she taught me. So what I've learned is that there is a beautiful side to brokenness that I remember one way to keep myself safe was to deeply believe that there was a beautiful side to the pain that I was experiencing in the moment.

Even if I couldn't visualise it, I just had to believe that one day, there would be something beautiful.

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.