



Chapter Two: “This is your child and you want to get it right”: Approaching end of life and planning for my child’s funeral

Featuring: Bec, Yvonne, Angela, Rachel

Unmasking Grief Series

Q. How did you begin to consider planning your child’s funeral? Who or what was helpful? (00:10)

Bec:

It's something that as a parent you never think you'll have to plan your child's wedding – Jesus that was – let me just retract that – I wanted to plan my child's wedding and I wanted to be the pain in the bum mum that was like, no, you've got to have this and you've got to have that and we've got to invite these people. That's what I wanted, but I had to plan my son's funeral. And it was really hard too because I was generally – the decisions usually fell to me because my husband was working full-time and supporting us and I just remember not wanting to make the wrong decision.

Angela:

There's a lot of practicalities that go into planning a funeral that requires obviously a lot of thinking and you're not really in a space to think through stuff, but this is your child and you want to get it right.

Bec:

I felt like I'd spent my entire motherhood journey just making decision after decision after decision, and there was so much weight on these decisions. This really was – it was my little boy's celebration of life and it had to be perfect and it had to be beautiful and it had to be him.

Yvonne:

I guess having a child who's older, you as a family can discuss what they would like. From music to who's going to speak, who's going to carry things up. How you want it to be, what church you want it to be. Whether you want to be buried or cremated. Dainere asked to be buried, so that was her choice.

Rachel:

I didn't consciously start planning for Evie's funeral, it just sort of happened. I was aware of songs on the radio if I was driving around that would just make me cry. I remember when Beyoncé's Halo came out and I realised – I was like, this is going to be one of Evie's funeral songs, and it was the same with Coldplay's Yellow.

Yvonne:

Dainere decided what she'd wear, what wig she'd have on, what she wanted in her hair. The colour coffin she wanted, the music or the people she wanted involved. It was Dainere's, so Dainere planned her funeral and we supported her.

Bec:

When Marc did pass away, it was quite sudden. He deteriorated very quickly and I knew at that time in my gut that when it started, I knew that this was different this time, but it wasn't – you hoped that he'd fought so many times in the past that it would still be like that. So we didn't have any plans. I didn't actually know what to do. I didn't know where to start.

Angela:

It comes at a time when you've just finished running an enormous marathon. You've really got nothing left in you because you've wanted to give it your all whilst they're alive, you wanted to give it all, empty all the love out of you that you could.

Bec:

I was very, very lucky and blessed that I had my best friend to help me and she found a funeral director who was able to guide us and help us.

Angela:

It was great for the pall care team just to subtly go, there will be an end point and then there's going to be a funeral. Just to plant the seeds of, well, what might that look like? You're holding this living being going, well, do I want your body burnt or do I want it eaten by worms? Neither option is suitable for your most beloved being.

Yvonne:

It's important that families, parents are supported early on, or at some stage, to have discussions about this and maybe just feel comfortable and safe to open up about it and in a safe space to talk about, what does it actually look like planning a child's funeral? What are some of the decisions that will have to be made?

Angela:

Going to the cemetery and then seeing all the other dead children's graves, I witnessed a man putting some flowers on a grave and I'm with Rosa in the car and I'm feeding her whilst Justin is out looking at all the different plots thinking about, well, which piece of cold ground will we put our daughter into?

Bec:

We do advanced care directives and we write down what our choices are for our child should something happen and they may need to be resuscitated or they may need to have lifesaving intervention. We've made these decisions and they guide the support and the level of support our child will receive, and I remember when we made that decision, how it took a weight off my shoulders. As odd as that may sound to some people, for us, we suddenly started breathing again and we actually were able to live.

Rachel:

It's weird planning your child's funeral when they're still alive. I found that really difficult and how to connect with anyone. I held that within myself. I didn't talk to anyone about that, because I thought it was weird. Yeah, I didn't want to be a downer to anyone, so I held it within myself. I think that I would do it differently now and I'd share that with other people. I didn't really even want to think about her funeral, but I just was aware of songs and poems and that helped, I think, to give me some sense of structure, but that's all I had in the beginning.

Bec:

Being able to have conversations around, yes, my child has a life limiting diagnosis. This will happen one day and being able to have discussions around maybe just having some loose plans or some ideas around what will need to happen and the processes. It's done then and you can go into the finer details at the time, but I feel like that would give you the ability to breathe and to know, I've done that. That's there now, now we live.

Q. What do you wish you knew about planning for your child's funeral that would be helpful for parents? (07:29)**Rachel:**

I wish I knew a few things about the logistics and, I guess, the process of the funeral. Especially the choice between burial or cremation. Before the moment, I'd only heard about these concepts. They were sort of abstract concepts to me. I didn't really know what either of them would physically look like, so I found it really difficult to choose between them and my husband and I didn't really know what to do. We were renting a home at the time and so we didn't know – we wanted a place for Evie. We felt really transient, so we decided that we would like to bury her so that she would have her place that would be permanent, that we could visit her no matter where we lived.

Bec:

When being faced with that decision to cremate or to bury, I didn't like both options. I thought, my child's going to be on fire or my child's going to be under the ground. I don't know – I couldn't – and I know that sounds really dramatic, but that's where my head went. I was like, how do you choose? It's such a personal choice to have to make and such a big choice that feels so final.

Angela:

Well, her remains were given to us in a plastic box in a bag that smelt like diesel fumes. The children's urns were next to the pet urns and I just couldn't – I don't know, there was just something really like, ah, I'm not expecting her to be cremated where animals are cremated and are there bits of a dog in with Rosa's ashes? Even the urns themselves weren't super clean and I'm like, I'm putting my precious child into this thing and surely you could get the grease off it. I don't know. There's just so many obvious things. Initially, the ashes were brought out in a really beautiful, little butterfly basket which my husband thought, ah, we get to keep that. But no, I think there must've been just one they reused over and over and they took that away and substituted it for this smelly bag.

Yvonne:

When we went to the cemetery, the staff there took us to a place where they thought we might like to bury her. It was in the grass area and I remember looking – it was in the middle of two other people. I looked at their headstones and those two people were both in their 90s and I remember saying, oh, you're burying – ah, I don't know if here's the right place between two people who got to live so long and it didn't feel right.

Rachel:

We chose burial, but I didn't know that I would hate that. I hated the feeling of her going into the ground. I felt like I couldn't breathe. I got nightmares about her decomposing and I felt guilty for not wanting to visit, because all I could think about was her underneath me. So it actually traumatised me going to visit the cemetery and I really hated the plastic stuff that people would bring to her. I remember people had obviously gone to visit Evie and then bringing things in that I hadn't approved of. I was like, how dare someone put a plastic, fake, crappy thing on my daughter's grave? So I'd get rid of them and I'd hide them in the bushes, or sometimes I threw them away. I didn't want that, so again I felt guilty for all of that stuff that I felt like I had no control over.

Yvonne:

So finally, they took us up to the monument section, the general headstone section and thank goodness they did, because that was up on a hill and it was in an area that was surrounded by trees and the sun was shining down. They took us to this area and it was called portion 17 and we actually live in a house that's number 17. So that's all right. Then there was row eight, which Dainere was born on the 8th and there was plot two, and she was born in February, the second month, so all the numbers came to, and I remember saying, oh my gosh, this feels, so, so right.

Rachel:

Speaking to the funeral directors, it was a few years later, I said, look, I actually am really distressed about this choice we made about burial. I'm having these nightmares and I feel like we made the wrong decision. We feel like it would be better if we could cremate her. What can we do about that? They said, actually, you can exhume the grave. So we went through the process of exhuming Evie and that was an incredible experience in of itself, just being able to have that freedom to make a different choice.

Yvonne:

We decided to buy the plots either side of her because we didn't want anyone else buried near Dainere, so she's between us two so that we can keep her safe, because we still want to keep her safe.

Rachel:

Then when we had the option of these ashes, it felt a lot better. Then it took us a long time to then scatter the ashes, but it gave us time. When somebody dies, when your child dies, there's only three days before a funeral maybe, maybe a week, and you've got to make a lot of very permanent choices in a very short amount of time, so having that freedom to then take our time meant the world to us. So just because you make one decision doesn't mean that you can't change your mind.

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.