

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department



Does the experience of losing a child expand or contract your world?

Parent Bereavement Group August 2023

We had quite a big group of parents present for this group, including 3 parents attending for the first time, and although their experiences all differed, they shared the common experience of surviving the death of their child. As parents introduced their child to the group, thinking about, remembering and missing their child was a common theme – *“My heart hurts everyday”*. One parent told us that she dreams about her child at all different ages.

The topic for the evening was a follow on from the discussion in the previous group where the topic was about making space for life amidst grief, and giving permission for contradictory feelings. This month we explored how grief impacts on your world and your life. Does grief cause your world to contract or does it expand the way you live your life? Exploring this topic, it became evident that different parents and families had different experiences and that for some this changed over time.

Some parents told us that after the death of their child they felt they became more inward looking and family-focused. One couple said; *“we spend more time just with the family.....you share with your family – they get it”*. *“It changes what you value and who you want to surround yourself with”*. Several parents commented how other people disappointed them, friends and family who they expected to understand and to step up just weren't there. Parents said they find they no longer *“sweat the small stuff”* and can find it difficult to participate in the everyday conversations of other parents. Your world can shift to be focused around those who do understand. *“Good friends and family are important. Grief changes what you value and who I want to surround myself with”*.

For another parent coping means trying not to change anything. She told us that every day she looks at the photos she took on that day when her child was alive, and remembers everything that happened on that day. She goes to the cemetery every day. *“This wasn't a choice, it's just how I get through. I rely on repetition. I feel like I have tried to keep my world minimal. I want to keep it to what I know and I don't want to share it”*. Many of the parents in the group expressed a fear that they would lose the memory of their child and that they wanted to keep their child in mind at all times.

Some parents told us how they cope has changed over time. One parent said: *“grief is hard work”* and in the early days her world did contract. She took 9 months off work and took up bushwalking, reading and writing. She told us she was always thinking about and talking about her daughter. She couldn't sleep and said she still wakes up every night. Going back to work was hard, seeing people again and slowly extending her world. Another parent agreed that it takes time to expand your world after the death of your child. For her and her partner, living and enjoying life was a conscious decision and a promise they made to their child. *“It was a conscious choice, but it took time”*.



Other parents in the group also spoke of their world expanding as a result of their child's death. There were parents in the group who had spent many years caring for their child who had disability and high care needs. For some of these parents being at home without their child is particularly hard. Being in a silent house without a million things to do is a constant reminder of the absence of their child. When talking about expanding or contracting their world, a parent told us *"I did the opposite. I was at home for 24 years. Now I have been working full time for 6 weeks.....I need a purpose"*. She wondered if she was compensating, as she felt she couldn't be at home, and she wasn't sure if she could manage to continue to work full time. She said *"I need to find a balance.....I have always put others first; now I'm learning to look out for me"* When your child has required 24 hour care, you have little time for yourself and your relationships. When your child has gone, you have a whole lot of time that you didn't have before – *"We didn't do things together for 14 years. Now we are going out for walks, but we still feel bad when we are happy. We would swap anything in a heartbeat to have him back"*. A parent who also cared for his son with extra needs talked about how he fills his day doing things his son used to enjoy, like walking through the local gardens and counting the fish in the pond. He does this when his other child is at school, as she doesn't want to talk about her brother at the moment.

Finding a balance is hard and can be an ongoing process in grief. Finding a way to balance heartache and happiness and to feel comfortable with periods of laughter and breaks from the intensity of grief without guilt takes time. A parent said: *"All you want, is to involve them in the laughter"*. Parents also spoke of feeling guilty if they realise they have not thought about their child for a little while.

"I need to find a balance.....I have always put others first; now I'm learning to look out for me"

As time goes on and if life is beginning to grow, these moments can increase – *"I feel guilty if I feel I don't think about him as much"*. Another parent spoke of the fear of the vivid memories being lost and no longer being always at the forefront of memory. As time passes the guilt generally lessens and many families find ways to keep their child present. Photos around the house, at work, tattooed onto one's skin are one way many parents keep their child close. A father shared how he kisses his son's photo which he has at work. Leaving a child's bedroom as it was when they were last in it, having a shelf or another special place for objects of significance to the child, keeping special objects from the funeral, carrying a particularly significant item with you are some of the many ways parents keep their child close. One family have bells in their house that were used at the funeral and the grandchildren enjoy playing with them, knowing why the bells are there and their significance. The power of scent was also raised with a number of parents speaking of how they try to keep their child's scent present. A father spoke of smelling his son's headrest in his wheelchair while others talked about smelling their clothes. A parent related a story of how she had tried to retain her son's scent on the last outfit he wore by sealing it in a metal box, only to discover that the outfit had gone mouldy over time and had to be thrown out. In relation to keeping special objects around, one parent said; *"He was here, he needs to remain in our lives"*.

Grief is a strange and unpredictable thing. A father whose child died over a year ago told us that it has only recently really sunk in that he is not coming back – *“I knew he wasn’t coming back but it has only recently really settled. I feel anger, especially with family and friends that I expected more from. I am slowly building some relationships back”*. The feeling of not being able to fully accept the reality of the death is not unusual and it can feel particularly painful when this reality finally hits home.

For those whose child is buried, visiting the cemetery is an important and significant ritual. Parents in the group spoke of the comfort and peace of the cemetery. A parent who regularly visits the cemetery told us that it is a surprisingly peaceful place and that it is a source of solace for her. She told us how she has come to know the other graves, who is visited and who is not. Other parents agreed with this. One parent said she feels calm when she is at the cemetery. Another mother told the group that for her things have changed over time and she does not visit her son’s grave as often as she once did but has discovered that her partner sometimes visits during his lunch break and ensures the grave is well looked after. This has become a natural part of his day. Yet another parent visits daily and brings fresh flowers every day. A family who had their child cremated told us they keep his ashes in a teddy bear that sits in his wheelchair. They also leave a small part of his ashes in the places they travel to and know he would have enjoyed – *“We take him everywhere”*.

A number of parents in the group talked about going back to work and their feelings about this. Going back to work can be difficult and requires connecting with others, some of whom may not know your story particularly if you are in a new workplace.

Within the group there were different experiences of returning to or commencing work with lots of different feelings. A supportive workplace made the experience easier. One parent had returned to work shortly after her infant son died – *“I couldn’t be at home thinking of the ‘should haves”*. Another parent told us; *“I went back to work after she died. I feel guilty every day”*. For some, returning to work is the beginning of expanding your world again. A parent is now working full time after being home caring for children for 24 years. For her this is a way of expanding her world and filling her time. Having a period without needing to be present among other people in the work environment can be very needed after the enormous impact of the death of a child. A parent who took 9 months off work told us; *“Going back to work was hard – seeing people. Wearing a mask helped, I could hide behind the mask”*. Most people knew about her daughter but she had experiences of people who did not know, asking her about her daughter and she spoke of the pain of telling them she had died. In most workplaces you must interact with others and that can be both challenging, as the time to think about your child is diminished and rewarding as you are distracted from your grief for a while and the workplace can present opportunities to talk about your child. As one parent said; *“She was real.....she lived”*, talking about her reinforces the fact of her life.

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People in the group spoke of the need to find a purpose in their lives. Some said they are still looking for a purpose and want to do something to help people in their child's name, another is setting up a scholarship in their child's memory. A grandmother has been knitting for the RCH auxiliaries for some years as a way of *'giving back'*. Finding new purpose in your life can be a way of expanding your world as a result of your child's life and death.

As this group was occurring just a couple of weeks before Fathers' Day parents in the group were invited to share with us what they plan to do on this day. Many parents are not aware that the week before Fathers' Day is Bereaved Fathers' Day and this could be a day parents mark before the general Fathers' Day. One father told us that his adult children have organised a family meal at a venue very close to where his daughter's end of life celebrations were held. He said this would be difficult, but he appreciated their thoughtfulness. Another family will have a big family gathering which will include the biological parents and siblings of their child.

He knows it will be hard, but it will also be good to be surrounded by those who knew and loved his son. For one family this will be the first Fathers' Day since their child died when they will be away and unable to visit the grave. They told us that this is a bit of a test as they are also planning to be away at Christmas which will be the first Christmas since their son died that they will not be visiting his grave as part of their Christmas celebrations.

As we finished the group we reflected that one of the lessons discussed this evening was the importance of *"you doing you"*. Common themes were raised and discussed, but everyone does things a little differently and everyone is at a different place in their grief journey. It is important not to be pressured by others into doing things differently or into feeling that the way you are grieving is somehow not the right way.

Thank you to all the parents who attended this group and shared their experiences and their wisdom.

Our letter box is waiting!

Contributions such as responses and reflections on the groups' themes, poems, letters, songs, review of books that you may have found helpful, quotations from parents, grandparents, brothers, sisters and friends, feedback about this newsletter are most welcome. Share your thoughts, experiences, questions with others who are bereaved.

Please forward them too;

Family Bereavement Support Programme
Social Work Department

Royal Children's Hospital

50 Flemington Road Parkville Vic 3052

Phone: 03 9345 6111

Email: Bereavment.services@rch.org.au

The next meeting of the Family Bereavement Support Evening Group will be held on:

Thursday 21st, September 2023

7:30pm-9:00pm

The RCH Foundation Resource Centre

Level 2, 48 Flemington Road

Parkville, VIC. 3052

Please join us to discuss the topic;
*Identifying our strengths and how to utilize them in living
with grief*

[If you wish to attend this group please email:](mailto:Bereavment.services@rch.org.au)

Bereavment.services@rch.org.au

The newsletter is always a team effort. Thank you to **Helen Stewart** for facilitating the group discussion and writing the newsletter, Thank You to **Shanti Petronzio** for scribing parents' statements. And thank you Lauren Palmieri for ensuring the newsletter is formatted, collated and distributed to interested people.



Social Work Department , RCH