

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER FEBRUARY 2021



Welcome to the first bereavement group newsletter for 2021. We held our February group over zoom. The zoom format allowed some families from more rural locations to attend, with 2 parents attending for the first time. In this group over half of the families attending had children who had been born with a disability, which added some extra dimensions to their grief as we heard during the evening.

### *“What Helps and What Hinders Grief”*

As in all groups the evening commenced with parents introducing their child to us and telling us a little about their situation. The lifespan of their children varied from almost 7 months to 15 years and several of the children had lived with disabilities throughout their lives or acquired disability for a period due to their illness prior to their death. A parent whose child died in an accident which she witnessed stated: **“I understand a bit about grief – I have been dealing with that since she was born, but I understand less about trauma. I don’t know where the grief stops the trauma starts”**.

All the parents have living school aged children and all commented on how hard it was taking their other children to school. **“I took (brother) to school and there was the absence of my daughter, there was an emptiness of not taking her to school also”**. Another parent whose child had significant

special needs said **“Taking the other children to school really set me off. Usually I would be training aides and attending school with my son”**. Another family had a child starting school this year and commented on how much their son would have loved to see his sister starting school and how the people at the school did not understand that her tears were not for the child starting school but for the child that was not coming to school.

In discussing our topic for the evening parents had many ideas about what helps them in their grief. **“Talking about him with the other children and family – he is a presence in the family’s life. Not a day goes by without us thinking about him. He is still there without physically being there”**. Keeping the absent child alive and



real in the lives of siblings who do not have a memory of them was also discussed. One parent told us how a sibling who has been born subsequent to his brother's death will sometimes say he misses his older brother. The other child who was 2½ when his little brother died responds with **"You didn't meet him, I'm his oldest brother"**. It is then a matter of unpacking that and explaining to the older child that a child who didn't meet his brother can still feel the loss in the family and the gap that should have been filled by the missing middle sibling.

Another helpful thing that some parents mentioned was having the deceased child's toys and possessions around the house. One quite newly bereaved parent said she was trying to decide what to do with her child's possessions – **"What will bring joy and what will bring pain and grief"**? The response from the other family is that it is both happy and painful – **"The other children like to play with his toys, it is a way of bringing him in to the lives of the other children. We are**



**able to tell stories to the other children about him through them playing with his toys"**. These parents commented that they find comfort in looking at their child's toys. **"It may bring pain, but it's a weird, comforting pain"**. They suggested that you don't need to rush to

decide what to do with your child's belongings; you need to take whatever time you need. The parent of a child with a disability told us that she did not want all his equipment in the house after he died, as she wanted to remember him as the person he was and not by his disability. **"We donated all his equipment. Passing on the items that could be used helped with the process. We kept a special box of his possessions"**. The need to look at restructuring the room when a new child arrives in the family was also discussed. This family was very reluctant to 'repurpose' their child's bed where they often sit to read stories to the other children. A solution could be to purchase bunk beds so that this special bed can remain.

Marking significant events/dates can be very challenging for families, particularly in the early days. One family told us that they took some ideas from the group and celebrate significant events in a way they believe their child would have liked. It was their child's 11th birthday just last week – **"the other children thought of ideas that he would have liked – eating ice cream, staying in a hotel and going swimming. We make his birthday fun rather than dreading the date. We create ongoing positive memories"**.

The conversation moved to a discussion of grief and expectations of others but, perhaps more significantly of your own expectations. One parent told us that one of the most helpful things she had to learn to do was to drop the judgement of herself. **"My grief counsellor helped me to give myself permission to feel what I was feeling without judging myself – to cry or not to cry, to be gentle and compassionate to myself, like giving myself a gift"**. There is intense emotion during birth, life

and death. She also shared with us that she felt some relief when her child died and the guilt she felt about this: **“How can I be grief stricken and relieved?”** Another parent said she also felt this sense of relief and then guilt that she felt this way. A parent commented that she didn't feel judgement from others, only herself. Some parents said that they had to let go of the feeling that there is a certain way to grieve and accept that there is no rule book. **“There is an assumption that there is a period of grieving and then you get over it. You need to understand that this is lifelong”**. A parent explained that in grief everything bombards her brain at once and her brain goes into overtime trying to tease out the different emotions. You can also get surprised with emotions and feelings that can come unexpectedly.

A parent told us about her feelings about how long friends and work colleagues could tolerate her grief. **“There was a massive amount of support at the start but a few months along I feel I have to keep the grief to myself and to function at work. My friends are tired and I wonder if they have the energy to be around me. I don't want to lose the support from my friends and from work. I am frustrated when my grief counsellor tells me these feelings are normal.....I need strategies to cope, to get out of bed and function in society”**. Another parent responded that she had decided to have a conversation with her boss about what she needed and that she would not be as productive as she had been. His response was that he would make it work as he wanted to keep her. She continued to check in with him about her productivity. Her experience is that friends can tolerate frank conversations. She told us about a conversation she had with her grandmother: **“My granny told**

**me that ‘it (death of her child) was meant to be’. I told her that did not help me at all, that he was not meant to die.....She asked, what does help and I told her that talking about**



**him and appreciating him helped. She said that was okay with her”**. This parent has found that she can have honest conversations with her true friends and that these friends grow with you. You are forced to be vulnerable and fragile but it helps when you can do this.

A parent who has been living with grief for 9 years said she keeps looking for and trying things that may help and that this is an ongoing process. Many of the suggestions have come from her grief counsellor. She told us that she just recently took up one such suggestion: **“I just learnt to swim and now swim in the ocean every-day. It is helping me heal in ways I wouldn't have expected, and this is 9 years on. I give everything a go”**. She also told us that she started a blog to keep people updated rather than speak to people individually. She also said that writing is helpful. **“Writing is very helpful. I may go years with nothing to say and then I just need to write. I have started singing. I nourish my soul, connect to**

**nature and connect to my child**". Hearing from this parent reinforced the knowledge that grief is ongoing and finding ways to live with grief is also an ongoing journey. One parent said: **"I have found red wine helpful. There is some opposition from loved ones about this coping mechanism but I find it helpful"**.

As a number of parents in the group had been living with a child with a disability there was discussion in the group about this experience – both the living with and the grief of losing the child. One parent told us that people sometimes asked her opinion on whether she would have the child without the disability if she had the choice. She spoke to us of separating the disability from the child and how the biggest sufferer was the child herself. When she became angry or frustrated with her child she had to remind herself that it was the disability she was angry with, not the child. There was a lot of pain about what she and her child were missing out on because of the disability. She said: **"I try to focus on gratitude, acknowledging that the disability was challenging but focusing on what the disability and the child actually brought to my life and the lives of everyone around her"**. She spoke about how much her child had given and how she had changed everyone around her. She said **"I wouldn't be the person I am now if it wasn't for her, I am so grateful for what she has taught me. My son is an amazing person because of her, he is wise, kind, and patient and doesn't see disability as a negative. He doesn't see difference in**

**his friends, he sees beyond society's norms"**. She described her daughter to us: **"She was so amazing, no ego, brave, lived in the moment, brought everyone onboard"**. This parent reflected on the enormous impact her daughter had on her life saying that she now has qualities she would never have had if she hadn't had a daughter like her – empathy, patience, non-judgement. She changed her job a few years after she had her daughter. She now works helping others who are coping with trauma and says she could not have done this without the qualities she learned from her daughter. She sees her daughter's influence on family, friends and work colleagues. Her legacy is significant and ongoing.



Other parents commented on the impact of their child's life on siblings. **"She has a different understanding of disability and illness. She matured quite quickly. She is very accepting of death, more than another child of her age who has not been exposed to death. She is more resilient"**. Another parent told us that her son reflected **"I learnt life won't go on as you thought it would"**. Parents also talked about the challenge of adjusting to parenting their other children after the death of the sibling who took up so much of their time. One parent spoke of how she initially found her other children boring and she missed the up and downs of her other child. Parents spoke of how their other children found the increased parental attention challenging and even unwelcome. A parent said **"I looked at my child and asked 'what did you get up up to these past 8 years?'"** One parent talked about the challenge and



**person I am now if it wasn't for her, I am so grateful for what she has taught me. My son is an amazing person because of her, he is wise, kind, and patient and doesn't see disability as a negative. He doesn't see difference in**

unexpected consequences of needing to untangle herself from her child when she died: **“Since having children, being a mum, that was my job, who I was. When my daughter passed away I had to let go of that and accept that her life wasn’t my life, that I hadn’t failed and accept that she is gone, but I am still here. In doing that I also disconnected from my son, my son is not my everything, parenting him is a job and my life is also important. How to let go of one but not both?”**

Readjusting to parent your living children can be a significant challenge. Another couple told us how they used to think of all the things they could have done if they didn’t have their special needs son. She said **“Now he is gone, those things don’t mean so much. Holidays, trips etc don’t have the same meaning that he had”**. His father added **“You always thought –is**

One parent talked about how much she had learned through her child’s life of the barriers in society to including children with disability. She said that until she experienced this, she had not realised what she had been doing to exclude people with a disability.

There was also discussion about the community you are exposed to when you have a child with special needs and the impact on your connection to that community when your child is no longer with you. One parent said **“This is a unique journey and there are only a few families who understand it”**. She told us that one parent from this group of parents asked if she would lose her as a friend now. Another parent said she had to sort out who were friends apart from their shared experience of having a special needs child. These people will remain friends regardless. Some parents talked



**this the hospital admission he won’t come home from, and imagine life without him. In reality, life without him is overrated. Grief is harder than the care. Life was more predictable with him. We are lost, we don’t know what to do, we just wander around the house. He created a lovely rhythm to life that was predictable, understandable and meaningful**

about the identity crisis they have experienced since their child died. **“I don’t belong to the group of mothers with children with CP but I don’t belong to the normal group either. I was a carer for 15 years. I am grappling with where I belong. It feels fake talking to the parents about house prices, real estate, the weather etc. I really miss the intensity of the conversations I had - mental health, hospital admissions etc.”**. Other parents echoed this

experience and spoke of the feeling of ‘fakeness’ in so many conversations with people who had not experienced what they had. Another mother said **“I am finding my place with my child’s friend’s parents, but I feel I’m not a part of it really. I feel like a grade 5 parent, but I’m not”**.

Many bereaved parents talk about their child’s legacy and the impact of their lives on others. In this group one couple talked about becoming involved in an organisation for children with the same condition their child had. They have raised money and have now been able to sponsor a PhD in their son’s name. There is now a student starting this year with this scholarship. They commented **“I wonder how he would feel about being a bit famous. His name will be mentioned when this student talks about his PhD. As a result of the scholarship a small finding or improvement may be found that could help another child. We are keeping our son alive in the family and the community”**.





*In this evening's group, participants allowed themselves to be vulnerable and share their feelings, experiences and wisdom in a way they probably cannot in other settings but which parents find they can in these groups.*

*I would like to thank these parents for allowing me to share their conversation with all the readers of this newsletter.*

## *Our letter box is Waiting!*



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

Family Bereavement Support Programme  
Social Work Department  
Royal Children's Hospital  
50 Flemington Road  
PARKVILLE VIC 3052  
Phone: 03 9345 6111  
Or email: [Bereavement.Services@rch.org.au](mailto:Bereavement.Services@rch.org.au)

The next meeting of the  
Family Bereavement Support Evening Group (Via Zoom)

**Thursday 18th March 2021 at 7.30pm**

**THE TOPIC FOR THIS GROUP WILL BE:  
'THE POSSIBILITY OF YOU – HOPES AND IMAGININGS OF YOUR CHILD'**

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

by Tuesday 16<sup>th</sup> March.



*The newsletter is always a team effort.  
Thank you to Helen Stewart for facilitating the group discussion and  
Ellie Kleid for scribing parents' statements.  
Also to Marina Puljic for ensuring the  
newsletter is typed, formatted, collated and distributed  
to interested people.*

**Social Work Department, RCH**

