FAMILY BEREAVEMENT SUPPORT PROGRAMME



Social Work Department

NEWSLETTER OCTOBER 2019

Welcome to the October 2019 newsletter of the Family Bereavement Support Programme. We hope that in reading the newsletters and being a part of the groups you will find connection with other parents, support and encouragement to help sustain you as you grieve for your child.

This month was a little different as our planned speaker for the group was unwell and unable to attend. With no set topic, parents were invited to discuss any issues, thoughts or concerns that were on their minds or that they wished to share with the group.

In the group were parents of children of varying ages who had lost their lives to a variety of causes, some anticipated, some completely unexpected.

The discussion began with a parent telling the group that she and her partner had very recently not only witnessed, but had been first responders to a tragic incident where a little girl lost h e r l i f e . She described the

post trauma responses they were experiencing, primarily not being able to get the images of the child out of their heads and also her distress with feeling that this trauma was taking away from her the time and space she usually has to attend to her own grieving process. She said that the death of their own son had impacted on her life enough and she did not want this experience to impact also.

Another parent shared her experience of finding her child in the pool and of how she called the ambulance and performed CPR while she waited. She said: **"I blamed my-**

> self, I wasn't supervising him myself, did Ι everything I could, called the ambulance, did the CPR, but I felt SO guilty". She told us how she had been in therapy and her therapist helped her to see what had actually happened by drawing diagrams and going through the events

step by step. It helped her to understand where her responsibility really was and that it was really not all her fault. She explained that this has enabled her to stop blaming herself and has helped her grieving.

Responding to the worry that the traumatic incident was taking over and interfering with the grieving process, another parent shared with us the

challenges she has with an older son who has very challenging and aggressive behaviours due to autism and mental illness. She said: "I realised that I spend so much time and energy dealing with him that I don't have time to grieve for my other son. I find I am resenting him for this - I love him and I know he can't help it but I still resent him taking away my time to think about my child". She is seeing a counsellor and has found it helpful when the counsellor described much of what she is experiencing as post traumatic stress disorder.

Another parent commented that for something to feel like it is bigger than the death of your child and is taking over your grief it has to be pretty big as witnessing the death of your own child is hugely traumatic. Another parent commented that things that distract you from your grieving can also be positive. He said it is sometimes good to get some respite from grieving.

One parent had recently celebrated her child's first birthday. She said she hadn't realised until after the party how much energy she had been putting into the planning of the

birthday. She had been planning for months and feels it was a way of distracting her self from her grief. It was only after the party that she felt she fell apart and was unwell for weeks.

A parent shared her experience of witnessing a trauma when she was a school girl. "We were at the tram stop and we witnessed one of the girls being hit by the tram. Because we were all witnesses we had to stay there and we saw all ambulances the and police responding. The image of the girl was right there, in the front of my mind all the time at first, but after a few weeks it eased. I hadn't thought about it for years". Another parent told us that she has learned to visualise a positive image when she is feeling traumatised. She said she chose the image she wanted to visualise very carefully as she wanted it to be a really positive one. She said she does find this helps.

A parent commented "Witnessing the death of your child is always traumatic, whether it is from a long illness or sudden and unexpected. The journey is different but the ending is the same". She told us that she has a very big picture frame with a



collage of photos of her child's life, including at the end of his life when he was very unwell. Even though the photos are all very small, she says she still finds looking at those last photos traumatic, but there are also a lot of happy memories in the photos.

Conversation moved on to the impact of the child's death on siblings as well as post trauma reactions in some A mother told us that her parents. second child recently had a quite serious bout of croup and they called an ambulance. She said she had never travelled in the ambulance with her first child, she always followed in the car and her husband travelled with him. "I always arrived in Emergency when they were shoving tubes and things into him. This time my husband said to me 'You're going in the ambulance'. I am glad he made me do that. I feel proud of myself that I was able to do it, but I also feel guilty that I never did it with my older son". Another parent told us about how panicked she felt when her child was going into theatre to have his tonsils out. Her first child had had heart surgery, and even though he did not die in theatre she felt very anxious when her second child had surgery - "I know it was

nothing like my other child's surgery, but it was really hard seeing him go to theatre".

parent acknowledged Α her hyper-vigilance regarding the health of her other children after the death of her child, telling us that she took her other child into Emergency shortly after the death when he only had a simple cold. Other parents also discussed their fears for the health and wellbeing of their other children, living and potential future children and their difficulty in trusting that they will be okay. "It's not like you get a free because something pass has happened to you - you feel like you need to be more protective of your other children because of **your experience**". A parent said "I thought my experience would make me a better parent, and I think in some ways I am but in some wavs it has made me a worse parent". Some parents described feeling they had become 'helicopter' parents. One mother said she will sometimes be watching television in the evening when her other child is asleep and suddenly feels she just has to go and check that her child is still okay. A parent felt the worry for other children was perhaps more intense



when you do not know what caused the death of your child or what caused the condition that led to the death. "When something causes your child to die and you don't know what it was medically, how do you stop worrying about that when you have other children and are planning future children? How do you stop worrying when you have no answer"?

One parent in the group only found out a diagnosis for her child after he had passed away. When she was pregnant with her second child she chose not to have testing due to the risk of miscarriage and because she would not have been willing to terminate the pregnancy anyway. Her husband said to her at the time "If we are destined to have two little boys with special needs for a short time I would rather do this than abort". She said she would never abort a child. "When I think about how beautiful he was I could never abort a child, even if it did have the same condition". After the

child was born they had the opportunity to test the cord blood. Even though she was sure the baby was fine she wanted the testing for her own peace of mind. The results came back clear but she says there is still a level of anxiety there even though he is now 5 and healthy.



This uncertainty can impact on decisions about future children. One parent said her thoughts ebb and flow between wanting and not wanting

another child due to her grief and her fear of losing another child.

Parents talked about the "what if" mindset. This included questions about things being different - 'what if I had done that', 'what if the doctors had taken me more seriously', and questions about what life would be like now or what the child would be like now if they were still alive - 'what ifwas here, what would s/he be doing, what would s/he think'? One parent said she hated being in this mindset as "it puts a bad taste in my mouth and clouds my thinking about the time I did spend with my child in his short life". Another parent who had two children after her first child passed away said she would only have had two children, so if her oldest child had lived one of the other children would never have been born imagine one Ϊ″ can't of my children not existing".

Siblings can be impacted by the death of their sibling in a number of ways.

Some parents spoke of their child's distress, or at least unease when they were unwell and had to go to hospital themselves. One young child had been very resistant to going to the hospital but after his time in the Emergency Department, seeing the fish and a meal from McDonalds he now wants to go to ED

rather than the GP. One parent said we now talk about "sick" and "sick sick."

One mother talked about her concern

that her two year old child does not remember his infant sisters. Another parent said, although their baby spent his nine weeks of life in hospital they were able to take him out of the room and have some

family experiences with him and his sibling. She feels their child was able to experience being а big brother for that short time and has memories of his baby She brother. feel does however that "I have bro-



ken his brother's heart and I feel guilty because of this".

Other parents told us how much a part of their family their deceased child is, even when the siblings never met him/her. A parent said they visited their child's grave on the way home from hospital with their second child and both he and his sister enjoy going to the cemetery, always say they have two siblings enjoy planning their and big brother's birthday celebrations as much as they enjoy planning their Another parent talked about own. how protective her child is of his baby brother's belongings. One parent told us that her nephew who is 18 months old and was born after her child had already passed away always wants her to show him the photo if his cousin which she carries

in her bag and blows him kisses.

The questions children ask can also be challenging for parents. Children are curious and want to understand how the world works. Their questions change

> as they get older and their understanding develops. A parent said that other people often try to fob off her child's auestions about death and trv to shut them down. Children do realise not that many adults are very uncomfortable talking death. about Children are able about to talk

death, to ask questions and to miss their sibling or wish they were still here with an innocence and honesty that few adults can. They are also able to distract themselves from sadness and play and still be happy well-adjusted individuals in spite of their grief. One parent told us that when he was reading a fairy book to his daughter he asked what she would wish for if she had two wishes. She said first she would wish for a pink unicorn and second for her brother to be back – highlighting the priorities in a small child's world are often not the same as in ours.

To finish up the group, parents were asked if they had anything happening the next day or over the week end that they were looking forward to. Some things were bitter-sweet as, while they would be enjoyable, there would also be an awareness that the child was not there.

One parent was going to а housewarming with a Day of the Dead This is a South acknowledgement. American tradition and it is usual to bring a photo of the dead person and their favourite food. She told us "I am going to bring his photo and I am not just bringing his favourite food but I am going to bring his lunchbox because he always knew that whatever was in his lunchbox was just for him". One couple were booking a holiday to Vietnam to get away and regroup as a family. Another parent said she had no plans for the week end and she was looking forward to this. A couple of parents had birthdays to attend, one family are going to the soccer together.

One couple will be going to the cemetery then, if it is nice weather, going to an apple farm – "We live in a estate and there are lots of new It is nice that just 20 houses. are in the minutes away you country". One parent said that it is hard being at home at the moment and coming to the group gives her a bit of light in her week. It is a time when she can spend a couple of hours just thinking and talking about her son. She did also tell us that she finds sewing relaxing and has recently won a prize for some of her work.



Many thanks to the parents who shared their stories, experiences and wisdom with us and allowed us to use their stories to write 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:

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<u>*If you would like to receive</u> <u>the newsletter by email</u> <u>please send us your email</u> <u>details to the provided</u> <u>email address</u>.*

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

> Thursday 21st November 2019 7:30 pm – 9:00 pm The RCH Foundation Board Room Level 2, 48 Flemington Road Parkville, VIC 3052

Please join us to discuss the topic:

Rituals that support grief

The November group will be led by Paul Hammat, head of Pastoral Care Services.

Please Join us in November

The newsletter is always a team effort. Thank you to Helen Stewart for facilitating the group discussion and writing the newsletter. Thank you to Lizzie McNulty for scribing parents' statements. Also to the volunteers for mailing assistance & to Marina Puljic for ensuring the newsletter is typed, formatted, collated and distributed to interested people.

