

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER DECEMBER 2018



Welcome to the December 2018 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.

“Looking forward, looking back-taking your child with you through the season of sun, family and celebrations”

This was our last group for 2018 and we explored together the experiences of those present with Christmases and New Years past, both with and without their child and thoughts and challenges about the coming weeks. We had people in the group for whom this will be the first Christmas since the death of their child. Many parents in the group also had other living children but for others there were no other children at home.

For many grieving parents it is very important to have a way of carrying their child with them through this time and to find a way of acknowledging the presence of their child in any celebrations, gatherings or special activities. People in the group were invited to join in an activity to create a piece of sand art to represent something of their child while they continued to discuss the topic for the night. The parents selected a glass jar/bottle and were invited to fill it with different coloured sand of significance to them or their child and place a candle on top. There were also various stickers and other small items such as stars, hearts and glitter available to add to the sand or to decorate the outside of

the bottle. While they were doing this activity they continued to share their stories and questions.



One parent said, **“I found it difficult to find the magic in Christmas until my second son was born. Now I have to create magic for a**

4 year old”. Other parents agreed that they felt like they were ‘faking it’ when they tried to enjoy Christmas. One parent who has now experienced quite a number of Christmases since her baby died said only now, with 2 other children and a number of years on can she really enjoy Christmas without feeling like she is faking. Another couple who now have a baby said, **“There is a want to celebrate it for her, but I just feel like I am pretending”**. There were a couple of parents in the group who had been through very difficult times

with their children over the Christmas period. They told us that for many years they relived those days every Christmas but now that more time has passed and other children have arrived these memories are no longer at the forefront of their minds. **"Last year was the first year I didn't relive every day in this period of time which is a relief really"**.

A parent whose child was born shortly before Christmas and lived only 6 weeks told us about her baby's first Christmas. They were in the Royal Children's Hospital having been hurriedly transferred from the birth hospital and on Christmas Day they were able to have a photo with Santa - **"We have one precious photo of him with Santa while at hospital which sits on the mantle with his sibling's photos..... We planned to redo Christmas when he came home. We walked into the house and the tree was still there. I said it needed to come down - I couldn't bear to have it there. My in-laws took it down for us"**.

A number of parents have established new traditions to remember their child at this time and other parents said they want to find a tradition or ritual that fits with them and their child. **"We established other traditions so we don't feel like we have forgotten him"**. Parents in the group didn't always find the right tradition for them on the first Christmas. One family were given a beautiful glass hurricane-type candle holder that holds a candle they light on the Christmas Day family lunch to remember their child and other grandparents who have also passed away since the child died. Another parent told us that she used to find a poem each year and someone would read it out before the meal on Christmas Day. She said they did this for several years but then they just stopped - it didn't feel like that particular tradition was needed any more. One family have established a Christmas Day tradition where the children

open presents at the cemetery and at home. This mother told us: **"We've not had a Christmas with my in-laws since he died because I can't be away from home"**. These in-laws live some distance away and cannot travel to them due to business commitments. The children also always bring their brother's bear with them each year when they have their photo taken with Santa. **"The kids tell Santa about their bear and that 'there are three kids in our family'"**.

Some of the parents in the group said that people don't always know what you want if you don't tell them. They acknowledged that it can be very hard to tell people what you need in the early days or years and often you do not know yourself. One parent told us how hard she found it when she was with her extended family watching the Christmas presents being distributed and opened. **"I will never forget that feeling of seeing the other children get presents and there not being anything for him. They didn't know that's what I needed"**. Once she was able to tell her family how painful that experience was, they were able to include a gift for her child.

The question of sending and receiving Christmas cards as well as other cards, invitations etc was raised. This is always a difficult issue, which can cause much hurt. Most people in the group want to include their child's name or some acknowledgement of their child when they send a card but find that few people are able to acknowledge their child when they send cards to them. A parent spoke for many in the group when she said, **"We want him to be acknowledged"**. Another parent said: **"It doesn't matter how many times I tell people or how many times I write cards, people don't write his name anymore"**. One person said it might be confronting for people to put the name in a card. Another commented: **"To me you're sending a card to half our family"**. One parent

commented, **"It's hard when you've told them what to do and they still don't do it"**. A parent said he doesn't include his child's name in a card if he is sending it to someone who did not know they had another child. It would be confusing to them to see the name of their second child in the card. Parents have different ways of acknowledging their child in cards. One couple sign cards with the three initials of themselves and their baby and a star for their first child, or his name or initial and a star. Others may name their child or preface the name with the word angel. One parent always writes on the left hand side of the card "Special kisses and angel wishes".

A couple who had needed to go to a shopping centre to do some non-Christmas related shopping said that it isn't just the decorations and the cheery Christmas music they found so difficult but the **"Christmas explosion of money...We are having difficulties with systems not understanding our circumstance so we don't have a lot of money at present"**. It wasn't just the money but the almost obscene consumerism that seems to take over at this time of the year that can be very distressing to people who know that there are much more important things in life than Christmas excess.

As we started to talk about plans for Christmas Day itself we found some people in the group knew what they would be doing and others still had no idea. One parent said that since the death of her mother this year the family has become more fragmented. She told us that her child remains at the centre of her plans for Christmas Day. **"I'm just going to try to do my best for him.....I have put Christmas decorations on his grave and people have told me they can see his lights from the street. He's shining his little light as people walk past"**. Another parent said, **"To have no expectations of the day is best rather than talk it up"**. It seems

some families are understanding about how grieving parents may feel at Christmas and what they may need while others are less so. One parent said of the first Christmas, **"They all wanted to acknowledge Christmas in some way, but it was really difficult"**. A parent avoided the most difficult parts of Christmas Day with relatives by doing the dishes and taking the dog for a very long walk. Fortunately the relatives were very understanding. A parent said, **"You want it to be as natural as it was, as if they were here, because you wish they were"**.

As discussion moved on the some more general challenges of living with grief a parent said, **"It's getting tough now because he is missing having a sibling.....Those are the things that are the dagger in the heart...they surprise us and pull us back into that dark place. It is those things, rather than a specific day that set you back"**. For this parent the day itself isn't so significant, it is just another day, albeit a special one. Other parents also talked about the questions their children ask and how this impacts on them. One parent said she had also experienced her child being upset about not having an older brother and asking her, **"Are you sure you did everything. Why didn't you get him a heart transplant"**. At the time her child was expressing his anger and disappointment about not having an older sibling she found this very distressing but has since wondered if this is more of a stage he was going through than a grief response.

A number of parents have experienced their child asking if they are going to die like their sibling. In those situations where the sibling had a diagnosed medical condition the parent can reassure the child that they do not have the same condition. This is more difficult when the cause of death was unknown. One parent said **"How can you be sure they won't die"**? The reality is that parents who

have experienced the death of a child know that life is unpredictable. A challenge is that children seem to come out with these questions at the oddest times when you are not prepared for them. One parent was surprised when her 4 year old asked if he was going to get holes in him like his brother did. She was perplexed by this question and she could not understand why he would think his brother had holes in him. Another parent suggested that perhaps he had got this notion for the movie Coco. As this was a favourite movie for the child this could well be an explanation. Like many parents this mother worries about her child's exposure to death and conversations about death. In other groups other parents have commented that they feel their children have less fear of death than other children and a healthier and more mature understanding of life and death than other children or indeed a lot of adults.

A parent whose infant had died said her toddler who had been very attached to the baby when he was at home told us that he still looks for him and asks where he is. A father whose son died twelve years after they had been told he would only live another year said his other adolescent children do not speak about him. He said, **"I want them to get on with their own lives"**. Another parent commented that the children are probably still trying to find a new normal now that their significantly disabled brother is no longer with them. Parents with a new baby said, **"We talk to her about him all the time. She beams at the photos...We try and make it normal for her"**. Parents talked about the connection between their children, ie the living and the not living siblings. In many families the children are very comfortable with the knowledge that they have another sibling even if they were born after this child had died. One parent commented on the different responses of her two children who were both born after their sibling had died. She

noticed that the second child was much less likely to ask the sort of questions about her brother that her other child had asked when he was her age. She shared with us her memories of when her second child was about 8 months old. **"I remember when he was 8 months old and he would babble, then giggle and babble some more. It was like he was having a conversation with another child. Someone asked me if I thought he was talking to his brother.....He seems to have a stronger connection to his brother than his little sister does. She is different"**.

Activities that seem to be quite normal, even mundane for many parents can take on a whole new meaning for grieving parents. A father told us about his difficulty going to the supermarket after his child had died. **"The supermarket was a fun place for us where we used to play while we were doing the shopping. It's hard to see other people screaming at or telling off their child"**. Another parent agreed that going to the supermarket in the early months was very challenging: **"I can't tell you the number of times I would go to the supermarket and see another baby then complete forget why I was there"**. Parents talked about the difficulty to being with other babies, particularly ones that were born around the same time as their own baby. One mother said her sister had a baby at the same time she did. While they were pregnant they talked about the cousins growing up together and looked forward to this. After her child died she found it very difficult to be around her nephew. She told us about a time her sister asked her to babysit her niece and nephew and what a disaster it had been with her needing to call her sister and tell her to come and get the children as she just couldn't do it. She said, **"How could she have even asked me to do that, and what was I thinking agreeing to it?"** This relationship has changed now and

she is close to her nephew. Another parent in the group also has a nephew of a very similar age to her son. She was shocked when he was brought to the funeral. At present she cannot bear to see this baby and finds it very hard to hear her brother complaining about him. She said **"It sucks to hate something you love. I can't hold babies anymore"**.

One mother who is quite recently bereaved told us, **"They're all just dancing around us. My brother had a child the week my baby died....he's a symbol of all the time that has passed"**. Another

parent commented that her child would be 9 this Christmas and she wonders what he would look like now and how big he would be. She said, **"There's no evidence that time has passed. For his siblings there's a lot of evidence like photos and clothes. In my head he is still a baby"**.

From this parents in the group began telling us about their feelings about the photos they have of their child. Many parents have photos of their child on display in their homes while others find it too hard to have photos around. Videos of the child bring them to life much more powerfully and a number of parents in the group said they could not bear to watch videos even many years on. One parent said, no matter how many photos you have, they are all the photos you will ever have – **"There's only a finite number of photos.....We have some we haven't looked at and that keeps him alive"**. They told us that they had a PowerPoint presentation of photos of him at his ceremony and it was so very hard to select just 100 images for this presentation. Some of the parents in the group had created photo books of their child as a gift to family, had created a scrapbook of images or had been given a photo book as a gift. A



parent told us how difficult it had been first to begin a scrapbook but then to actually complete it. She had done this over a few years. She said she is still tempted to go back an 'improve' the book but her husband and an art therapist friend said it is what it is now and she should not change it. Another parent said, **"We have photos of him all around the house from all stages of his life....We haven't been able to put a photo on his monument yet. Putting his name on it was hard enough"**. Choosing one photo is hard – **"Do you put one of when he was a newborn, or of when he was at home and looked a bit more well? Do you choose one when he had no tubes or one with his prongs and nasogastric tube? It is so hard to decide. We want to be true to who he is"**. Like the mother struggling to finish the scrapbook, it is also somehow making the whole thing more final, more complete. While this is still outstanding then it is still a work in progress, a tangible task you still need to complete for your child.

There were different experiences with the comfort of family and friends taking about the child and of the reactions of families both in the early months after the death and further down the track. There are many things that can cause much pain and distress which others are not always sensitive to. Extended family and friends varied in how much and how easily they talk about the child. One parent said they used to talk about him but over time this stopped happening. Another parent said people didn't want to mention their son for fear of upsetting them. She said, **"I wish they would upset me. I just want to hear him talked about"**. Another parent told us how she would get annoyed when her family continued to do things after her child had died, **"My sister went to a concert after he died and I thought, how can you do that, my baby has just died? They don't do those**

things now our mother has died, but why did they do them after my son died”? Another parent responded, **“Life goes on”**. Even when you feel like life has completely stopped, for others this may not be the case. A father told us that after his son had died he was angry when he saw that the tree at the end of their drive was in blossom. He said, **“I was annoyed with the tree for growing. It’s not rational, but I wanted to pull the flowers off. I didn’t feel like that this year”**.

We had a brief discussion about New Year. Some parents finding the turning over from one year to the next very difficult as yet another year begins without their child alive in it. The parents in this group had not found this time to be exceptionally challenging but one parent said, **“The joy and frivolity seem pointless”** and another added, **“If I could have a New Year’s resolution it would be to have him back”**. Most parents agreed that they would be going to bed well before midnight on the 31st December.

As the group had been sharing their thoughts and experiences they were also working on their sand art candles. At the end of the group they all shared the significance of what they had created. A parent who had used red sand with some glitter and some stickers on the bottle said **“Red was his colour, he was always drawn to it. He loved cars so I put some car stickers on and an arrow pointing up”**. Another parent who has used a lot of blue in her jar said, **“He had blue eyes. They had just settled on blue”**. One parent told us that she spent a lot of time in hospital with her child and when they were on the ward they could sit in the window and watch the sunrise and the sunset together. She remembered how the light would shine into the room. She recreated a sunset in her sand art. Another parent had used stickers of flying things, planes and butterflies to decorate the bottle. She said she wished she could just fly up to be with her son. A parent had a train on the bottle and said, **“Some people get off the**

grief train at different times but I’m still on it”. One of the parents told us how a wattle had blossomed outside his son’s window when he was in ICU and they had watched it every day. **“Yellow is his colour”**. He had used a number of colours in the bottle – **“We like to see colour in the world. The world is beautiful and he made our lives beautiful”**. There were some earthy colours included by some as they are grounding. All the bottles were beautiful and unique with meanings in the art for each parent and child.

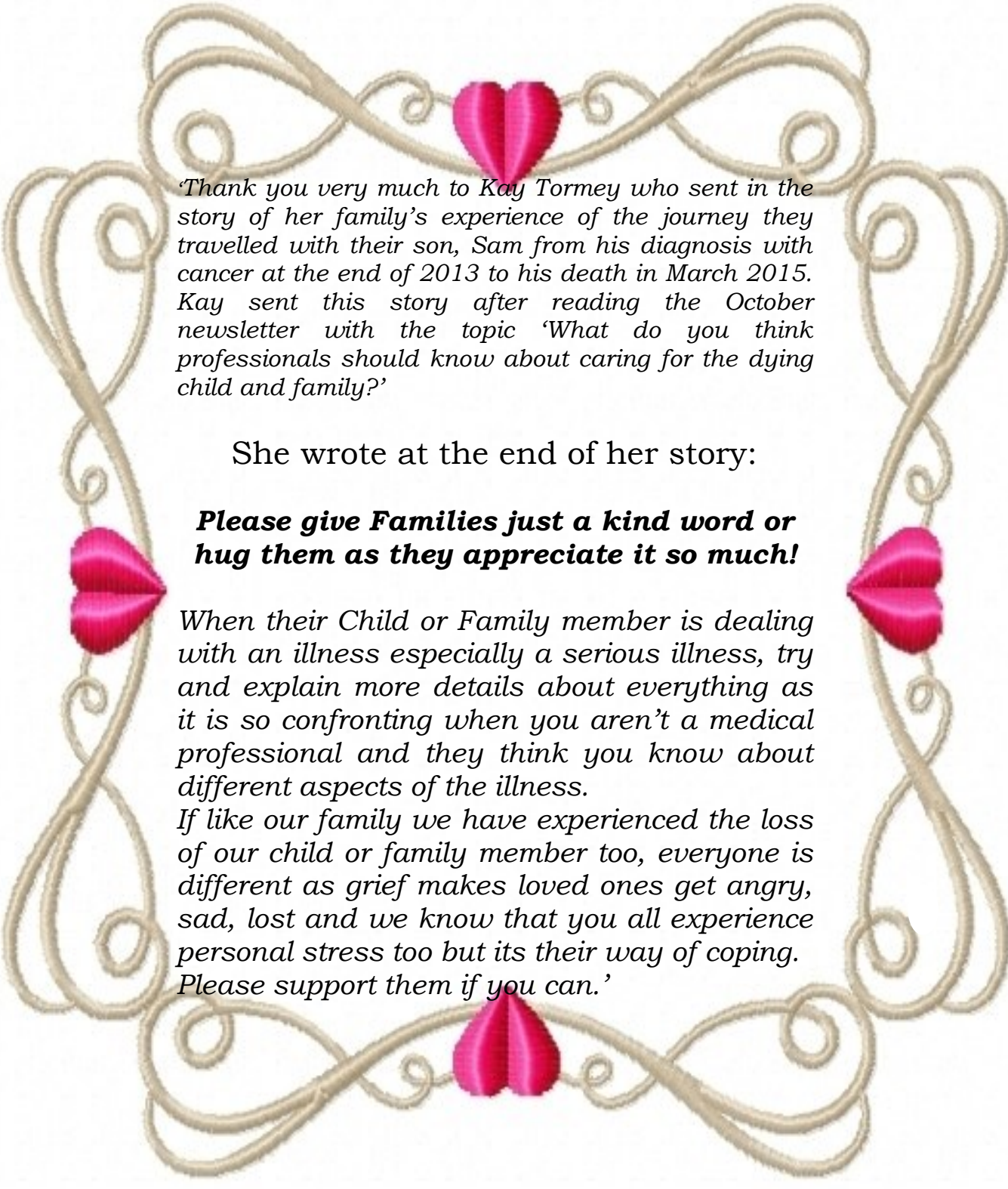
A final quote from a parent in the group – **“We are all different people now – it’s been forced upon us”**.

This was the final group for 2018. I would like to thank all the parents, friends and other family members who have shared their stories, their wisdom and their challenges so openly, generously and honestly both through the groups and through their contributions to the newsletter throughout the year. All the staff at the hospital who have had the privilege of being part of the groups and the creation of the newsletter – myself and Robyn Clark as facilitators, the people who scribe so this newsletter can be created each month, the staff who put the newsletter together and see that it is emailed and posted to you hope that you have all found some comfort, affirmation and a sense of community from reading the newsletter each month.

May you find in the coming weeks time to acknowledge and honour your child and the impact that the gift of his or her life, however brief has had and continues to have on you and your family.



Straight from the Heart



'Thank you very much to Kay Tormey who sent in the story of her family's experience of the journey they travelled with their son, Sam from his diagnosis with cancer at the end of 2013 to his death in March 2015. Kay sent this story after reading the October newsletter with the topic 'What do you think professionals should know about caring for the dying child and family?'

She wrote at the end of her story:

Please give Families just a kind word or hug them as they appreciate it so much!

When their Child or Family member is dealing with an illness especially a serious illness, try and explain more details about everything as it is so confronting when you aren't a medical professional and they think you know about different aspects of the illness.

If like our family we have experienced the loss of our child or family member too, everyone is different as grief makes loved ones get angry, sad, lost and we know that you all experience personal stress too but its their way of coping. Please support them if you can.'

Our letter box is Waiting!



Contributions such as responses and reflections on the groups' themes, poems, letters, songs, 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

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

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

**Thursday 21st February 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:

Moving between Loss and Restoration: the Rhythm of Grief

“The ‘Dual Process Model’ of grief acknowledges that the experience of grief is not linear, but involves two processes of grieving, one which is ‘loss-oriented’ and one which is ‘restoration-oriented’. February’s group will invite participants to think and talk about the changing rhythm of their grief, and share how they experience the movement between being focused on the loss and at other times focused on restoring their investment in life”

Please join us in February

The newsletter is always a team effort.

Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter and to Sophie Harris for scribing parents' statements.

Also to the Administration team for mailing assistance & to Marina Puljic for ensuring the newsletter is typed, formatted, collated and distributed to interested people.

