FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER AUGUST 2018

The Royal Children's Hospital Melbourne

Welcome to the August 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.

"Stories: our children's stories and our own as we navigate our changed lives"

In the group this month, parents were offered the opportunity to share stories of their child or their family in a setting where others were able to listen to what was often too hard to express to those who have never experienced the death of their child. This evening parents chose to share the stories of their child's dying as well as their living. Many of these stories were filled with emotions that were almost impossible to put into words and certainly very difficult for others who had not had similar experiences to understand.

One of the parents attending the group is expecting a child in the coming weeks and as people gathered there was discussion about the 'bitter-sweet' experience of having a child after experiencing the death of the older child. The parents talked about the difficulty of feeling excited during this pregnancy – ***"I just want this baby in my arms"***.

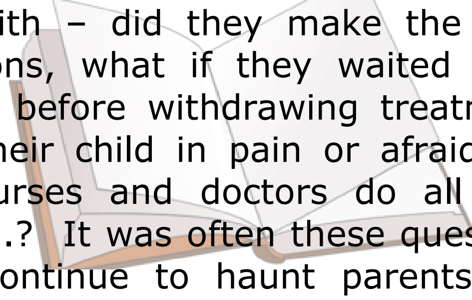
They also spoke about the frustration they feel when other people think this will 'fix' their grief – ***"people tell us that it is great that you are moving forward".*** Another parent said ***"It doesn't fix what you've been through"***. Others in the group who have also had children subsequent to the death of a child agreed with these sentiments and had also experienced pregnancy as an anxious rather than joyful time. Some parents told us about their shock when they saw how alike their babies were – ***"When I saw the 3D scan I couldn't believe how like his brother the baby was – there was the same nose, exactly like his brother, they are so alike"*** Another parent also talked about her shock when her second child was born looking exactly like her first. She now has three children – ***"Their baby photos are on the wall all together. I know which one is which and their father does but other people***

always have to ask us which baby is which, they are so alike." Parents also talked about the importance of the team who are caring for them during their pregnancy and birth understanding their situation and accepting their emotional reactions may not always be what they are expecting.

Following this early discussion parents introduced us to their children and themselves and were invited to share their stories with the group. All parents were able to share photos of their children, either on their phones or a special photo they had brought with them to share. Seeing the photos of the children we were hearing about somehow made the stories more personal and more real.

We heard that some parents in the group were aware from early in their child's life that their child may not live for very long, but for other parents this expectation was not there, even if their child did have some health challenges, death had not been discussed or expected until shortly before it actually happened. For many parents, living with the uncertainty of their child's condition was very stressful.

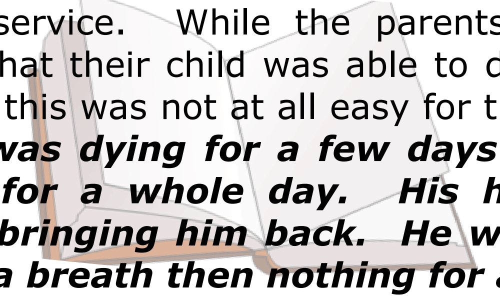
As parents started to talk about their experiences of the end of their child's life a common theme was the doubts, regrets and what if's that parents still live with – did they make the right decisions, what if they waited a bit longer before withdrawing treatment, was their child in pain or afraid, did the nurses and doctors do all they could...? It was often these questions that continue to haunt parents well after their child has died.



A parent shared the story of her child's last days in the hospital. He spent about 80% of his life in the hospital and we were told how the hospital felt like home and the staff like family. ***"They told us he had 2 weeks to live. I believed them, I thought he had literally 2 weeks, 14 days, but he only lived a week. One week is very different to 2 weeks… Three days before he passed we took him out to the park in the sun. He looked different. It was as if he knew it was different. There was almost something adult about him".*** We heard that they took him out again the next day and although the mother felt he was not comfortable and wanted to turn back the nurse suggested that it would be fine to continue on to the park. When they did return to the hospital, mother quickly went to the toilet and while she was in the bathroom her baby had a crisis. ***"I blame myself, I was in the bathroom when he arrested. I really regret that".*** Their baby died the next morning. ***"I woke up at 5am the day he died and he was hot. No one told us what dying looked like. I asked the nurse if he was dying and she said she couldn't tell us that. We wanted a definite answer".***

The parents shared a photo of their child with us – a beautiful boy with a huge smile. We heard about how he had several major heart surgeries in his short life and how he so often bounced back, how he could go ***"from 100 to 0 in just a few minutes"*** and how his mother had learned to be a strong advocate for him. She felt that most of the time staff listened to her as they recognised that she knew her child best. The few times she was not listened to are the times she remains hurt and angry about as she feels her child then suffered more than he needed to. These parents also told us of their mixed feelings when they were told that it would no longer be appropriate for their child to be put on ECMO* or a ventilator again. They had witnessed a very traumatic intubation and resuscitation of their child at one time and never wanted him to die like that. – ***"I couldn't even get near him. I could only hold his hand for a few seconds. I was told he was going to die. I did not want him to die like that".*** In the end this beautiful child passed away in the arms of his mother with both his parents with him. ***"I read him a book as he was passing away. It wasn't until later that I realised I hadn't read him the last page. He will never know what was on the last page".***

Other parents told us how they had no indication that there was anything wrong with their child until very soon after his birth and even then, after a time in intensive care they took him home believing they had a healthy child. As it became evident that he wasn't developing normally he was brought to the Royal Children's Hospital for further investigations. His father said – ***"We were prepared for a disability, but not for death. You think about life with a child with a disability and you think 'Yes, I've got this', but you are not prepared for him dying… In the end the time from diagnosis to death was 5 weeks".*** This child had a very rare genetic disorder and once it was diagnosed they realised that many of the things they had done to determine the diagnosis actually hastened the progress of the disease. While this was heart-breaking for the parents they realised that it was not anyone's fault and do not regret that these tests happened. They chose to palliate at home with the support of a palliative care service. While the parents are glad that their child was able to die at home this was not at all easy for them. ***"He was dying for a few days and died for a whole day. His heart kept bringing him back. He would take a breath then nothing for ages then he would come back again and take a huge breath then nothing – this went on for 5 hours".*** It is very difficult for parents to say that they wanted their child to die, but when you are watching them and wondering if they are suffering and know death is inevitable it is not unreasonable to wish the process was over and your child could be at peace. These parents told us – ***"We wanted him to die but he wouldn't die… The last week before he died he couldn't do anything, he was a vegetable, trapped in a body that couldn't move. His heart was too strong; he kept coming back. You can't really talk about baby euthanasia".*** They also told us this beautiful story of their child's dying – ***"At 4pm he was dying and magpies came and sat on the back fence and sang. Magpies do not usually sing at that time. Something in the air changes as the soul leaves and the energy brings native birds".***



In response to the comment about death happening over a period of time another parent agreed and said ***"He was actively dying for over a week. You can't explain it. Friends never get it, they can't comprehend it. They think you are alive then you are suddenly dead".***

Some of the parents in the group felt that as soon as their child died they immediately looked different. One parent said – "***They change as their soul goes".*** Another parent said that they had been told that when their child died they would just look like they were sleeping and that some parents would want to keep their child at home for a while, but this was not their experience – ***"As soon as he died he looked completely different."*** For another parent, the experience was quite different. She said – ***"We had him embalmed and took him home. I think he looked just beautiful".***

We heard the story of a child who had been born with some abnormalities in his liver and heart with related health issues. Like some of the other parents, although they knew their child had some health challenges to live with they never thought he was going to die. These parents brought a beautiful photo of their child on his third birthday, with a huge smile and clearly having a wonderful time. ***"We knew he was sick on the day of his birthday party but we decided to go ahead. He had a great time and all the family were there. After he was very tired. Five days later, the day before he was due to have heart surgery he suddenly had a massive bleed and started to vomit blood. I waited 12 minutes for an ambulance and couldn't call (husband) while I was on the phone to 000. When they arrived they took him straight to Monash".*** At the hospital he had further bleeds and as they couldn't work out what was bleeding they couldn't stop it. ***"I watched them perform CPR 5 times. I wanted him to have a peaceful death, not to die with people jumping on his chest".*** The decision to turn off the life support was very hard but they knew it was the right thing to do. ***"There were enough signs that told us he was gone. He was telling us 'I'm done'. He died instantly once the machines were turned off. It was the machines that kept him alive".*** While these parents were very sad that they were unable to hold their child in his last days, they were pleased that family members were able to come and say goodbye to him and he was able to say goodbye. The third birthday party 8 days earlier had been his going away party although they didn't know it at the time. His parents told us that in his 3 years he had many hospital admissions, lots of procedures and tests, in fact something happening every week, yet he took it all in his stride and coped beautifully and was always happy. At the end he was 'just done'.

Another mother in the group also talked about the pain of the final days of her child's life. Like some others in the group she knew her child had problems with his health and development but at the time of his death they still did not have a diagnosis although he was almost 3. She had also experienced him bouncing back from some other health crises and was not expecting him to die. The last time he did not bounce back but continued to deteriorate until the decision to turn off life support was made. ***"The neurologist was so gentle. She was pregnant at the time".*** Unlike the previous child he did not die immediately but continued to live for 3 days. His mother told us she asked to be transferred back to the ward rather than remain in ICU and they had a private room with mattresses on the floor so they could all sleep together. Someone in the group asked if she had wondered if she had made the right decision when he continued to live but her response was –***"We had a photo of him stuck to the cot. He wasn't the same boy. He was having constant seizures and his little face and eyes were constantly twitching. I kept asking them to increase the morphine as he wasn't comfortable. The process was exhausting and so traumatic. I was holding him in my arms and watching him when the social worker came and asked if I wanted her to heat me up some lunch. I looked up to say yes and when I looked back he had gone. He waited until I looked away".*** She told us that her husband has the photo of their son tattooed on his arm.

The final story shared with the group was of a little boy born with a heart defect and brought to the Children's Hospital for surgery. Initially they were trying to let him put on weight and grow a little before surgery. On the week end the parents went to rest and only about 15 minutes later were called back to be told their baby had a cardiac arrest. CPR was started and he was transferred to ICU and put in ECMO. He had his surgery and returned still on ECMO. He then started to have blood clots and was taken off ECMO and had an MRI scan of his brain. The neurologist then talked to the parents and grandmother and words like 'neuroplasticity' were used. ***"When we came out of the meeting my mother and husband were very hopeful. I know how to read a brain scan and I knew the damage was too great for any neuroplasticity to be relevant. I told them there was no coming back from that. We had to ask for another meeting and this time it was with the head of neurology who agreed that the brain damage was not recoverable... Everything seemed to happen on a week end or public holiday – it was over Christmas. Something would happen on the week end then during the week things would seem to be moving in the right direction then on the week end something else would happen".***

Parents also shared how they managed the spaces and items at home that had been their child's. ***"His room is still set up. Gradually we have moved his things to his room. Now it is a place to go to be with him, a place to cry. I always spent time with him on a Saturday morning. Now I go into his room".*** And another couple who are expecting another baby said they have decided that some clothes will never be shared, the memories of their child in those clothes are just too strong, but other clothes that he wore will be shared with his new sibling as will his pram, bassinet and car seat. ***"It was tough cleaning the pram, bassinet and car seat and sorting through the clothes... It was 12 months before we could have any kids in the house. Now when children come there are some toys they can play with but others that are put away in our child's room that are not to be touched. I still sleep with***

his bunny. We will always have (child's) bedroom".

There were many common themes discussed in the stories. Parents' concern about their child's suffering and the experience of their child was always present – what were they thinking? There were also some memories of beautiful things staff or family did for parents at this most awful time. A parent told us how one of the nurses asked if they would like her to take some photos of both of them with their child – ***"I would never be able to get that opportunity back if she didn't ask".*** Another parent also had some photos of herself and her husband with their child when he had passed away and all the tubes had been taken out. One photo was just of their hands. She says she looks at the photos but her husband cannot. She made the photo of the hands black and white and put it on face book to finish a compilation she had prepared to the music of 'Over The Rainbow' for his birthday.

When parents had shared their very moving and honest stories of the last days of their child's lives we decided to finish the group with a special memory of each child. One parent told us how she remembered seeing the first photos of her child when he had been transferred to RCH while she was still at the birth hospital after having a caesarean. She said she cried because he was so very beautiful. She also told us he had a turned eye and how his eye was always straight after he had surgery and had lots of muscle relaxant drugs on board. She remembered his cheeky look when he pulled out his nasogastric tube which he did often and how he thought he was so funny when he farted and would giggle as he was still farting.

Another parent told us one of her favourite memories is of when she would tell her child to show his funny face and he would scrunch up his face and sort of snort through his nose. He was always happy. He also liked to pull out his nasogastric tube and she came home one day to find he had pulled it out and her husband and put it back in, aspirated the clear fluid to confirm it was placed properly, taped it up etc. She was astonished.

A parent whose child lived for only 6 weeks said she always read 'Guess How Much I Love You' to him throughout the pregnancy and continued to do this after his birth. Her husband had also bought a storybook for him while she was pregnant and he heard these two stories every day. The day they drove home from the hospital after he died there was a full moon that looked like it was right over their house. Her husband said ***"I think he is telling us he is alright".*** Since then, the moon has become a symbol of her child and some friends will even send her photos they have taken of the full moon. Her second son looks for the moon whenever they are out late. She also told us that the day her child died they took him out of the hospital to the helipad, as he had never been outside. She has since had 2 more children and one day they were playing at the park outside the new hospital and saw the helipad was still there. She was able to take the children there and tell them that their brother had also been in this spot. ***"It's the only place that all three children have been as the old***

hospital where he spent his life does not exist anymore".

A couple said that their child was not a child who gave away smiles easily, he made you work for them. His father said he really liked this about him. He loved music and bebop and animals. They played classical music to him throughout the pregnancy and he continued to love this music. He told a very funny story about an interaction with a young music therapist at the hospital which didn't quite go as planned. His mother said she was always frustrated that she would be with her child all day and no matter how hard she worked at it she could never get a laugh out of him but as soon as his father got home he just had to say 'boo' and he would start laughing. She said ***"dad was the funny one but he always came to me when he wanted cuddles".*** His parents also told us that his symbol was foxes. They decorated his room in a woodlands theme and people just started giving him foxes as gifts. This was never planned it just happened sort of organically and now this has become somewhat of a symbol. ***"Friends of the family will see a fox and will message us and say they saw a fox and thought of him".***

Lady beetles had become a symbol for another child. Beetle was the first word he said and that became lady beetle so now they have lots of lady beetles in their garden. We heard how affectionate this child was and what beautiful hugs he gave. He also liked to kiss whomever he was hugging on the lips so his kinder teacher would always get a hug and quickly turn her head so the kiss landed on her cheek. His mother misses these beautiful hugs the most. She commented that the hardest thing about holding her child after he had died was that he could not cuddle her back – ***"There is nothing sadder that hugging a child when they cannot hug you back".***

This group felt very special as parents shared together some of the most painful times of their lives. These are stories that can only be shared with a very select group of people who can understand the honour these experiences. Some things cannot be put into words and some things are almost impossible to even say aloud. Unless you have also experienced something similar it is almost impossible to understand and to accept the truth of these stories. Amongst the trauma and the pain of these death stories there was also the love and the joy these children brought to the lives of the families, and their families brought to their lives. Every parent in the group wished only that their child did not have to suffer and that they had a happy and full life. Every parent in the group continued to be the best parent they possibly could be right to the moment of their child's death and beyond. Thank you to all of you for sharing these very personal stories with the group and with all those who read this newsletter.

*ECHO: Extracorporeal membrane oxygenation which is a technique of providing both cardiac and respiratory support when the heart and lungs are unable to provide an adequate amount of gas exchange to sustain life.

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:

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Social Work Department
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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 20th September
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:

"Expressing emotions through music"
One of our music therapist, Melina Roberts will be leading this group.

Please join us in September

The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter and to Ellie Braitberg for scribing parents' statements.
Also to Carlee Maggs from Holmesglen TAFE and Administration team for mailing assistance & to Jenny Jelic for ensuring the newsletter is typed, formatted, collated and distributed to interested people.

Social Work Department, RCH