

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER APRIL 2019



Welcome to the April 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.

"Including your child in Easter rituals"

The April group was held on the Thursday before Good Friday and was well attended. We welcomed some new people to the group as well as others who had attended previously. We were very aware that before the group would convene again several significant days would have come and gone – Good Friday and Easter Sunday, ANZAC Day and Mother's Day. In the course of the evening we discussed the significance of these days for those present.

Parents in the group felt that Good Friday and Easter Sunday held different significance for them. Of those in the group that night the religious significance of Easter was generally not important to them. One mother, who is herself not religious but her husband was, said they will not go to Church over Easter as they usually would have, as her husband is so angry with God. They will also eat meat on Friday, deliberately not observing the tradition of eating only fish on Good Friday. They will have

an Easter egg hunt for the other children. This would have been their child's first Easter and his absence will make this a particularly hard time

Several parents spoke of the significance of the RCH Good Friday Appeal for them. They spoke of their appreciation of all the hospital did for their child: **"If it hadn't been for this hospital we would not have had the 9 weeks with our child that we did"; "I am so appreciative of the hospital and the time we had with our baby"; "This was his home"**. A parent told us she had happy memories of Good Friday in hospital with their baby son. It was a day when he was quite well and he met Molly Meldrum. She said, **"I can smile thinking about it (Good Friday) but I am really sad inside"**. Another parent told us she takes her other children to the Kid's Day Out and other parents participate in Run For the Kids. A mother told us that she had permission to wear a T Shirt to work

with her son's picture and name on it. She also asked to work on the registers the week before Easter. She said she managed to raise a lot of money for RCH this week as customers asked her about her son and then felt moved to donate. She said, **"This is the first year I have done this. I couldn't have done it before but I was ready and it felt really good to be taking about him"**. One parent said of Easter – **"Easter Sunday has never been particularly significant for me, I will focus on teaching his sibling about the Good Friday Appeal"**.

Not all parents had such a positive attitude to the hospital and the Good Friday Appeal. Some expressed mixed feelings or changing feelings while others felt anger with the hospital and said they would rather donate to other charities. A parent told us when she was pregnant with her child and already aware that he would need to go to the RCH immediately after birth, she found seeing a child who looked really sick on the Good Friday Appeal too confronting and distressing, knowing her baby would be there after he was born. Another parent told us that after her child died she was initially drawn to watching the appeal and anything to do with RCH, looking for nurses and staff she knew. However, later when she turned off the television she would be angry, angry about the good stories **"what about the kids who don't go home"**. These stories are never told. As time passed, however she began to think – **"if not for the money raised we could never have got our child's diagnosis"**.

Other parents also expressed frustration and anger at difficulties with diagnosis, the lack of facilities in Australia to do some diagnostic tests and the decisions made regarding research funding. One parent said: **"The neurologist didn't have an answer. This didn't make sense. I was so angry"**. This parent also told us that they were accepted onto a trial with genetics, which meant they had results back much more rapidly than usual. These results did not help to explain what was happening with their child, however. She said, **"There are limits to genetic and medical knowledge. It is frustrating, knowing that the Good Friday Appeal helps to progress research"**. One parent told us that they did not get a diagnosis for her child until months after he had died. While she is very appreciative that they did eventually get a diagnosis she is surprised that now, years later, these tests are still not done in Australia. The mother of a child who passed away from a brain tumour said **"I can't understand why we had to go to Peter Mac for radiation. They didn't understand him there. The nurses at RCH loved him and it would have been so much better for him to have his radiation here"**. She was astonished that when the new hospital was built the capacity to do radiation was not included. She was also surprised and angry that when she donated her son's tumour for research, **"his tumour was only the 7th donated"**! Another parent who lost her child to SIDS told us that she has no positive connection with RCH. She avoids posts about RCH – **"I don't want to hear about it"**. She is angry that Red Nose (formerly SIDS and Kids) no longer raises funds for SIDS research and she said, **"It is**

crazy to think that RCH does not do any research into SIDS". She does not contribute to the Good Friday Appeal but raises funds for an organisation that funds research into SIDS.

Easter Sunday is associated with chocolate and Easter Egg hunts for many children and for some families it is also a family day. One parent explained that for his family Easter does not hold any religious significance but Easter is a time of joy, family, children and excitement. His child is now old enough to be excited about Easter eggs but he is also very aware that his brother is not here. **"The activities around Easter heighten the loss".**

Another parent told us that her father recently passed away, her mother is in a nursing home and the family is rather fractured at present. She said when her nieces and nephews were young she always had an Easter Egg hunt at her house to bring the magic to the children. Now she has a young child herself she is disappointed none of her siblings does this for him. She has decided to have an Easter egg hunt and has asked her family to come to her house to help to create this magic for her son. She is hoping her family will come and put their differences aside for at least that day. She said she did not need to do anything special to bring her other son into the day as she feels his presence at all times.

Another parent said she buys her son chocolate and has wrapped a gift. On Sunday half of the family will go to the cemetery. Another parent also said the family will go to the cemetery on Sunday.

For some families Easter is not celebrated or acknowledged – **"I don't do anything. My 6 year old misses his big brother. He was the joy of the house. I don't do Christmas or Easter – I don't even mention it".** Another mother said, **"I am trying to brush it off, but it's a significant first, thinking of what he would have been doing".** For another parent Easter had not really entered her thinking as she had been concentrating on the first birthday since her son's death – he would have been turning 4.

Most parents are very appreciative when other people remember their child and Good Friday can be a time when they wonder if the people who were very significant to them at the hospital remember. A parent says she thinks of all the nurses who love him. She says she sends things to the ward every now and again with her son's name to remind them of him. She was tempted to send something for Easter but decided not to. Another parent told us how much she loves to hear that her son is not only remembered by his doctors but that his name is still used in teaching about his condition and in trying to learn more about it. She still has contact with someone from the team and one of his specialists keeps his photo by her bed. A mother told us, **"I remember he was part of the furniture at the hospital and people cared about him".**

ANZAC Day did not hold any particular significance for the people in the group but Mother's Day certainly does with most parents saying they were much

more anxious about Mother's Day than they were about Easter. Most in the group said they were dreading the day. One father said to us on this one day he feels he really does not know how to support his wife. He said: **"We normally go to the beach and throw twigs and flowers into the bay, we light tea light candles. Mother's Day is harder than Father's Day – I don't know how to support her"**. A mother said in response to this father's distress that nothing her partner could do on that day was right. **"I tell him I want him to buy a big present but then when he does I say that it is too big and I wanted something else. No matter what he does he cannot make me feel okay. I am always just angry"**.



A number of people in the group had fractured relationships with their own mothers and said this makes Mother's Day even harder. Some mothers in the group said their own mothers want to make the day all about them and their grief at the loss of their grandchild. Some mothers in the group felt they had to go along with what their mother wanted even though this was not what they would want to do – **"My mother will ensure that everything is about her, but it will be a big deal if I ignore her"**. This mother told us that her mother would not acknowledge her child as she says it is too upsetting for her. Another parent described her mother as 'toxic'. A parent in the group who had recently lost her own

mother and had a fractured relationship with some of her siblings said she had a **"complicated but loving relationship with my mother. I miss her and sometimes I think of the loving things and I am sad then I remember other times and I am just angry with her. I am jealous of everyone who gets to celebrate Mother's Day"**. Facing Mother's Day as a single parent is particularly hard. A mother in the group who is in that situation said it is often very lonely but sometimes she is glad she does not have family to worry about as she also had difficult relationships with family members. A parent in the group told us that, when she was pregnant, her mother had told them they should not be having another child. When family relationships are fractured

an already difficult day can be made even more difficult.

A number of the parents present talked about finding cards and other mementoes from their child. One mother told us that she was cleaning out a drawer and found a Mother's Day card from her child from last year. **"It was like I was back to the first months after he was gone. I am only seeing the card now for the first time. I think he is trying to tell me something. I think he is trying to remind me to have a good time and be happy. But I don't know how to be happy"**. Another mother told us that she has a card from her baby son at home. It has an outline of his hand at 6 or 7

months. It makes her think of the Mother's Day they had at home with him. As he was not well enough to be at home very often this was a very special time.

Other parents talked of the mementoes they have of their child. One parent has the hand and footprints of their baby who tragically lived for only 2 days. Their baby had tiny hands and large feet – perhaps she would have been a tall girl. Another mother said she was unable to keep many of the mementoes of her son as they went through a period of being homeless and she was unable to keep a lot of her things. The group had a conversation about when and how you pack up your child's things.

One parent said she felt she had packed up too soon as she had been angry and just wanted to clear things out. She said she kept a few special clothes of her child's but gave most away. She said she is pleased that some other babies in the family are able to wear the clothes her child never was able to enjoy but she regrets packing up the things so soon. One parent said **"His things are everywhere in the house. I don't know what to do with everything"**. The very clear advice was not to let anyone rush you – you will do it when you are ready.

One mother told us that on her first Mother's Day she went to the footy with her dad. By the second Mother's Day she had her second child. She was very upset when people kept wishing her a happy first Mother's Day. Now she has 2 other children she said she feels guilty that

she cannot enjoy Mother's Day when her children are so excited about it. **"I am always going to be grumpy on Mother's Day"**.

The parents in the group agreed that Mother's Day is the hardest day of the year regardless of how many years have passed or whether there are other children or not. Several parents agreed that no matter what their partners do they can never make it all right.

When trying to explain why Mother's Day is so very difficult a mother said: **"Mother's Day is about acknowledging me as a mother. The mother should not have to make plans and decisions about the day. The man is responsible for working it out. That's why it is such a mess"**. It was acknowledged that there are high expectations for the partner and he can probably never get it right because there is nothing right about celebrating Mother's Day when one of your children (sometimes your only child) is not there. For one mother in the group her wish is that her partner will be there on Mother's Day. He works week ends so is rarely with her on a Sunday. She does not want to keep reminding him how important it is for her to have him with her that day but she is fearful that he will forget and she will be alone. The group agreed that it is his responsibility to get the day off and he should know how significant this is.

Another couple told us that for the first Mother's Day they went on a trauma retreat. They felt this would have been quite good except that there was a baby there who was the

age their daughter would have been. This made being present with the baby very difficult.

When finishing up the group each parent was asked what they think their child would have appreciated most about their mothering. For some this was a difficult and emotional question to answer. One parent who had been breastfeeding her baby said: **"He used to make me laugh. He loved the boob, yes definitely the boob"**. Another parent responded: **"He would say he's okay, he's proud of us, that we have learnt the lesson, that we're gentle and loving"**. For another parent - **"He would be grateful for all the love. A palliative care nurse reflected that you could really tell that he was loved and that he felt loved and nurtured. Those words were so important to me"**.

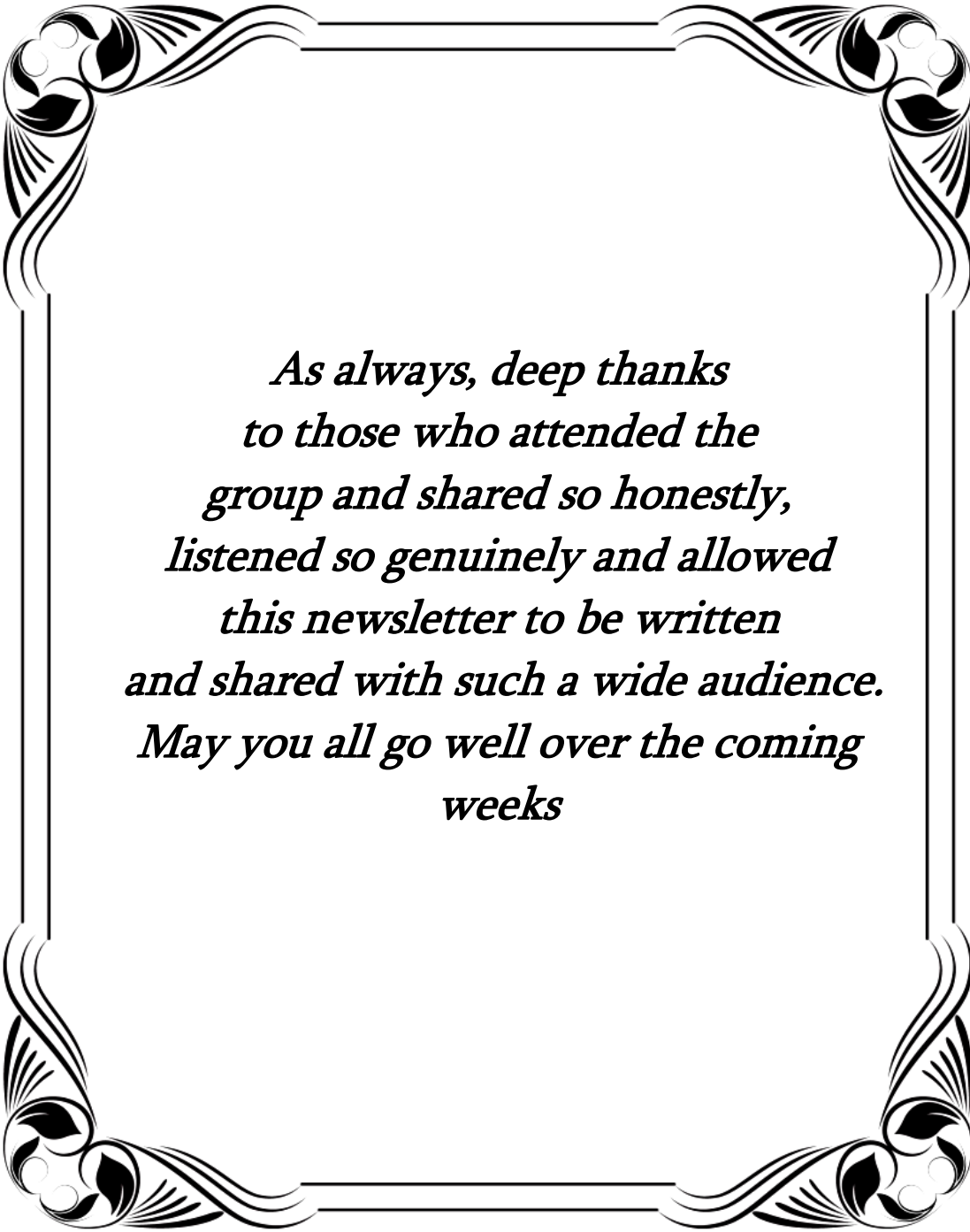
A mother told us - **"She would have thanked me for the perseverance to have her and she would have known she was wanted"**.

One mother said she felt her baby had a very special connection with his brother, more so than with his parents. She said whenever his brother came in his seizure activity would diminish or stop and he would drink his bottle. She felt this is what he most appreciated in his short life.

Another parent said she wished she had heard her child say "mummy" as he was non-verbal. She felt he would most have appreciated that she was his advocate - **"He would have said,**

thank you for being my voice and for being my best advocate". Several other parents in the group also felt their child would have appreciated their advocacy for them, even when this advocacy was to allow them to die. One parent told us that she knew from her child's MRI scan that he could not live and she made the decision to ask that his life support be turned off. She said: **"It was not the right decision for us but I know it was the right decision for him"**. She also said she would have loved to see him smile. Another mother also told us that her son had been very close to his father and his father had died not very long before he was diagnosed with a tumour and died. As he was approaching the end of his life she told us he was very excited to be going to heaven to be with his dad. **"I told him his dad was waiting for him and it was time for him to go to him. It was so hard but it was the right thing for him"**. Being a good parent in such circumstances is about thinking what is best for your child no matter how much it tears you apart.

Those in this group shared powerful feelings of grief, of anger and, for some of appreciation for a hospital and staff who could not save their child but had tried and had cared. A parent had brought in some wrist bands created by a bereaved parent acknowledging being a parent of an angel and acknowledging International Bereaved Mother's Day and International Bereaved Father's Day. International Bereaved Mother's Day is on the 6th May this year, the week before Mother's Day. International Bereaved Father's Day is also the Sunday before the conventional Father's Day. You may like to look



*As always, deep thanks
to those who attended the
group and shared so honestly,
listened so genuinely and allowed
this newsletter to be written
and shared with such a wide audience.
May you all go well over the coming
weeks*

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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Royal Children's Hospital
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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 16th May 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:

“The public and private me - coexisting with contradiction“

Please join us in May

The newsletter is always a team effort.

Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter and to Claire Gaunt 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.

