

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER FEBRUARY 2018



The Royal
Children's
Hospital
Melbourne

Welcome to the February 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.

“Back to business - Another year without my child”

For our first group of the year we discussed how people had navigated the holiday and New Year season with the various celebrations and family expectations, and how people were travelling in 2018. We had people in the group for whom this was the first New Year they had navigated and others who had done this many times. Some were newcomers to the group, come to share their stories and hear the stories of others. One couple pointed out when introducing themselves and their child that this was the first time they had said their child had die 'last year'. Others in the group identified with the pain of this.

People attending the group had different experiences of Christmas. One parent who has another child said **"Our other son is getting to an age when he knows what Christmas is about, so we decided to embrace joy for the first time"**.

This father said that to be joyful is a conscious decision and one that is not always possible or easy to fulfil.

Another parent said they have just started to enjoy Christmas again after many years but this year her father died only 3 weeks after being diagnosed with cancer just before Christmas so it was again a very sad time. She said **"Christmas will always be a difficult time with the double grief - now two people are missing"**.

A parent for whom this was the first Christmas said **"Christmas was terrible. All my nieces and nephews look like my child. We just survived. We went for the family"**.

Another parent said **"I didn't want to be around family, I didn't want to be around any high notes. I feel lonely, I'm still on a different note to everyone else"**.

Other celebrations were also discussed,

particularly when significant anniversaries are close to Christmas. One parent whose child was born just 2 days before Christmas said they celebrate his birthday every year but it is a small celebration with those who are particularly close. Her child died 6 weeks later and as life moves on the marking of this anniversary has changed. **"This year we didn't acknowledge it the way I would have hoped. One of the children was at school and we could not do a family activity the way we usually do. We still went to the cemetery"**. This baby lived for one January and this month is always difficult. His mother said **"I don't think of what was happening then every day of January now, but I still just survive January"**.

A couple who are now entering their second year without their child said this second year felt **"a million times worse... The second year has eaten me up... I am expected to just be okay with things"**. One parent who has also just experienced her second year told us that she has been seeing a counsellor and is now taking medication. She said **"I know medication can't fix grief, but for me the bottom was just too bad. It is hard to know what's what"**.

This is something that has been said by other parents many times in this group and an experience that those in this group who had experienced their second year could identify with. We spent some time in the group discussing experiences of how things change over time.

Expectations of others:

Some of the challenge of the second

year and indeed subsequent years were to do with the expectations of family and friends – **"Other people tell you how to grieve"**. In general it felt like others expected you to be 'back to normal' now a year had passed. One parent said that every time she does anything that looks like a 'normal' activity such as going to a movie, everyone thinks she is somehow over her grief. Because of this she is reluctant to do these things. **"I worry about people thinking 'you're better now, you're over it'. Sometimes I just want to be stuck in my grief"**.

Many families celebrate particular days or anniversaries related to their child such as birthdays and anniversaries. The attitude of family and friends to these celebrations can be very hurtful. One parent told us about her sister's fury when she asked her 4 year old nephew if he would like to blow out the candles on his (deceased) cousin's birthday cake. This parent told us that she spent several years trying to get her family to celebrate significant days with her but in the end decided she was only making herself miserable and changed the way she celebrates, so that now a much smaller but more significant group celebrate birthdays and anniversaries. Another parent chose to celebrate her child's first birthday at the cemetery and was very aware that those who did come were uncomfortable with this. She was very hurt recently when no one came to her marking of sweetheart's day.

One parent in the group lost his job (his contract was not renewed) after his child had died suddenly. The loss of his job, which he loved, compounded his grief. He commented, **"It is so hard to start your life again, to try to be**

bubbly in a job interview". He was recently called after a job interview and told he appeared a little 'flat' in the interview and if he was given the job could he guarantee to leave this 'flatness' aside? This by someone who knew about his child. It is also hard to be happy for others as they celebrate a pregnancy, a new child or an achievement or milestone of their child. The experiences of those in the group were that some people understand this and are very sensitive and considerate while others have no understanding at all and can be offended by your apparent lack of interest. The experience of one parent whose sisters cannot understand why she is unable to show excitement and joy at their pregnancies and subsequent arrival of their babies contrasted to the experiences of another couple who told us that friends arrange to have their children babysat when they come over.

This issue of others' expectations and inability to understand grief is a theme frequently raised in this group and ran through much of the discussion this evening.

Changing relationships:

Many parents talk about their disappointment with the family and friends they believed would support and understand them in their most difficult times. As parents in the group discussed, not only do you have the grief of losing your child but you also experience the grief of losing your circle of friends. Parents who had been bereaved longer said they have tended to build a new circle of friends – some who were friends before and some who were known but not close friends. Sometimes the most unexpected people understand and become your

closest friends. A person who had been a close friend of one of the people in the group but seemed to disappear, then told her later, after she had her own child that she had no idea of what she was going through until she had a child of her own and even now she could not imagine how she would feel if she lost that child. One member of the group said **"You get better at surrounding yourself with people who are gentle on your soul".**

Coming out of the fog:

A parent commented, and others agreed that the first year is all a bit of a blur, it can feel like you are operating in a fog, just getting through each day with no energy to really think or analyse what you are doing or feeling. Parents in the group felt that this is largely a trauma response and that the death of your child is a trauma and it does not ever really go away. As one parent said **"The trauma never really goes away. If you have had an accident and lost a limb people can see that you are different and they don't expect you to be the same. Grief does not leave any outward scars so people do not understand".** Another parent who has just experienced her second year without her child said **"I'm still confused about time, the shock is always there... coming here feels surreal".**

Images, regrets, decisions:

Everyone in the group said that they carry some traumatic images of their child and particularly, but not only after the first year, parents reflect on the decisions they made and question if they should have made different decisions.

One parent commented that you have

to make decisions, particularly around funerals at the worst time of your life when you can hardly think at all. There are also decisions for some about treatment for your child – **"maybe we shouldn't have agreed to that last surgery when he seemed so well before he had it"**. Another parent told us **"You remember the images you saw and you play over in your mind the 'what if's'. We wonder about if another surgery caused trauma and should we have done that"**. One parent said **"I want to hold onto the memories but I don't want them to be traumatic, like the sound of the beeping machines"**. Many of these decisions can only be evaluated in hindsight, and at the time you make decisions based on what you believe is the best thing for your child. Unfortunately we do not have the ability to look into the future. A parent who, with her partner had to make the heart breaking decision to turn off life support said that after that decision she can now not make any decisions. She said, **"Other people ask me to let them know when we are ready to come over. Don't they understand I can't make decisions, they need to just tell me a date"**.

Time heals, doesn't it?:

"Time does not make the pain go away, it is about the decisions you make". This was the consensus of the group. The pain never goes away, you just find ways to live with it.

Siblings, having another child:

The impact of having another child, or the need to make sure your child's sibling/s have a good life was another powerful issue in the lives of parents in tonight's group.

One parent told us, **"I don't feel like my lights turned on until I had another child"**. This parent had waited over 7 years for their second child and she commented, **"This was the right amount of time for us. I don't think we would have been ready sooner"**. However there was still **"massive anxiety about having a healthy child"**. One parent said, **"The day that the baby got to the age our child was when he died, I had a big sigh of relief. I know this is not a guarantee that nothing will happen to them... I would like to wrap them up in cotton wool but it's not good for them"**. Having a new life in the family was seen as distracting and as providing a new purpose.

Some parents talked about having high expectations of themselves as parents to a new sibling. They found, however that they are human after all and are still a normal, imperfect parent to their subsequent child while still loving them and appreciating the fragility of life so much more than other parents.

Parents talked about their child's legacy, how to honour them and what they promised them. **"We promised him we would continue to live, love and laugh... It would be very easy to hold on to the negative things but that's not what we promised him"**. Parents agreed that it is a conscious choice to look for the light and it is a very difficult thing to do. Other children provide a distraction and a strong reason to look for ways to find a way to live positively – **"there is a feeling of not wanting to bring the new sibling down with you"**. One parent saw having a good

life and being happy as a way of honouring his child. It is, however a conscious effort and is not easy. Another parent said she did not want to go out and do things but **"he would want me to do things"**.

A couple in the group were expecting their second child and asked how they tell this child about his/her brother? They were concerned about how to keep their first child a part of the family and to give their second child an understanding of what had happened. One parent told us that her young child had only had 7 weeks with her little brother. They want him to know his sister and for her to remain a very real part of their family. A parent said she had also worried about keeping the child present in the family as other children were born, but a friend whose oldest sibling was still born told her, **"I can't remember the first time I was told about my sibling. She was always just there"**. This parent went on to say that they have just integrated their first child into their family, **"We just answered his questions at appropriate times. His siblings go to the cemetery, they send him bubbles and talk about him very naturally"**. Most parents in the group had experiences of other children asking very direct questions and of making direct statements, such as a child coming up to the parent during a family function and stating that their child was dead. It seemed it was the adults in the room who were uncomfortable with this straight forward honesty.

A number of parents worried about answering children's questions

appropriately – **"Am I answering them the right way?"** One parent shared the story of her niece asking her where the child's bed was. On finding no cot in the room she stated **'of course, he needs his cot in heaven'**. A parent who is a primary school teacher told us that the children in his class had to grow up very quickly when they had a grieving teacher return to the classroom. He said by the end of the year the children had changed – they were much more empathic, not only to him but to the other children in their classroom and in the schoolyard. Clearly there are benefits to children being exposed to the reality of death and being allowed to talk about it.

In contrast to talking to children about death a parent raised the issue of talking to strangers or people you may not know well about your child. He asked how other people respond when asked if you have children or how many children you have. At first he avoided the questions or said he did not have children, as it was too hard to cope with what may come next. He never felt right about this and now feels he can start to say he does have a child who is now not with them. His partner commented that she wants to acknowledge her child but this is not easy as others do not always read the cues – **"It is important to acknowledge and honour him, but it is hard to shut down the conversation – people do not know how to read the social cues, people feel uncomfortable or it becomes about them"**. Other parents commented that they have had the experience of people 'running a mile' when they hear you have lost a

child and not wanting to talk about it at all.

Understandings of life, death and living a good life:

One father shared with us the journey of his family following the death of their second child. He told us he felt angry and frustrated for the first 12 months and then he and his wife decided that could not continue to live like this as it was unfair on their other child and they did not want him to grow up hating his brother. This family have now experienced a different cultural understanding of death as they lived in Bali. He explained that the Hindu belief about death is very different to the western belief that he sees as very dark and very final. He explained, **"His soul made a deal with his god, he only needed to learn a few lessons in life, our family needed to learn lessons about gratitude for life... He taught his family that lesson. He was here for the time he needed to be here. Now the family need to live a fulfilling life"**. This understanding has helped the family a lot but it is still not easy to live a grateful life. He feels honoured to have been the parents his child chose. **"Love and gratitude now guide our lives rather than anger... This event happened, I can't change that, it's how it effects us"**.

This parent also gave us an image of grief – he said that he and his wife lived in 'The Grief House' after their child died. All the windows and doors were closed and they did not look out. Whenever they did open a window or door a crack and saw some light from

outside they slammed it shut again. Gradually they began to open the house a little and saw that there were some good things outside the grief house and they began to look out, then move out. The Grief House is still there and sometimes they still retreat into it, but most of the time they live in the light - not an easy choice but one that is made consciously every day.

A parent said, **"You don't know love until you've got kids. It is not like any other love... we've missed that love"**. Parents talked about the signs they see that their child is still present with them, things that are both reassuring and painful as they are also reminders of the loss.

As the group came to an end a parent said **"You need to be gentle on your soul, do things in your own time"**. All agreed that if we could surround ourselves with children life would be so much easier.

Many, many thanks to the people in the group who shared their stories, their experiences and their beliefs so openly and honestly in the groups and allowed this newsletter to share these with so many more bereaved parents.



Straight from the Heart



Little Boy Blue

The little toy dog is covered with dust,
But sturdy and staunch he stands;
The little toy soldier is red with rust,
And his musket moulds in his hands.
Time was when the little toy dog was new,
And the soldier was passing fair;
And that was the time when our Little Boy Blue
Kissed them and put them there.

"Now don't you go till I come," he said,
"And don't you make any noise!"
So, toddling off to his trundle bed,
He dreamt of the pretty toys;
And, as he was dreaming, an angel song
Awakened our Little Boy Blue —
Oh! the years are many, the years are long,
But the little toy friends are true!

Ay, faithful to Little Boy Blue they stand,
Each in the same old place,
Awaiting the touch of a little hand,
The smile of a little face;
And they wonder, as waiting the long years through
In the dust of that little chair,
What has become of our Little Boy Blue,
Since he kissed them and put them there.

Eugene Field. 1850–1895



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
address.****

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

**Thursday 15th March
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:

“Reflections on decision-making in the most difficult time of your life”

Please join us in March

*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 RCH Volunteers for mailing assistance & to Jenny Jelic for ensuring
the newsletter is typed, formatted, collated and distributed to interested people.*

Social Work Department, RCH

