

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER DECEMBER 2017



The family bereavement group met just 11 days before Christmas in the midst of 'the silly season' with some parents unable to attend due to school or kinder graduations and a number of other end of year commitments. In all this hustle and bustle it was good to have a quiet place to sit and talk about how to navigate this season while living with the grief of a child missing from the family.

“Tis The Season To Be?”

As is the case most months, we had a mix of parents in the group. Some parents had experienced a number of Christmases and New Years since the death of their child, some only one and for some this would be their first Christmas and New Year without their child. We also had people familiar with the group and others who were coming for the first time. This mix of experience, as always was of great benefit to the participants in the group.

Those parents who had experienced Christmases without their child shared their experiences and the



things they had learned over the years. One parent said, **“This is the first Christmas it feels like a weight has been lifted and we can enjoy it”**. Another parent told us **“I felt like I was faking it for the first years”**.

The feeling of having a weight lifted or of being able to start to enjoy Christmas again was, for these parents associated with having another child reaching an age when they were old enough to really be excited about Christmas, usually around 3 years of age. **“The joy of Christmas for a 3 year old has brought back joy for us”**. For one couple their child did not experience Christmas as a 3

year old. They commented, **“This first Christmas without our child is the first Christmas he actually would have registered it and enjoyed it”**.

While discussing significant days and how to survive them some parents shared with us how they had navigated their child’s birthday and 1st anniversary of his death – 2 days which were very close together. For his birthday they had a celebration with a small group of people who they were quite close to. For the anniversary they stayed close. **“After we visited him we thought we would go to the beach but decided on the day that we just wanted to go home”**. This theme of never planning anything without the option of changing your mind continued to come up throughout the group.

Over the years, a number of parents who have attended the group have shared their stories of going away to avoid



Christmas for the first few years. A parent in this group told us that they escaped to Bali for the last few Christmases. **“We used to go to Bali to escape and to help get through and not have to explain to people”**. He also talked about connecting to the more spiritual way of thinking about life in Bali which felt much more meaningful than the commercialisation of Christmas in Australia. He told us that this is the first Christmas they are embracing since the death of their child, as their first child is now 5 years old and can understand Christmas. He also said **“we have tried to stay happy for Christmas so he doesn’t hate his brother for us being sad at Christmas time”**.

Another parent also reflected on how much they had learned from their child about what is important in life. This is their second Christmas without him and they commented: **“We are ignoring Christmas this year”**. Their child attended a special school and last Christmas the school gave them an elf they had made with a photo of their child’s face, hands and feet. The elf was holding a little sign which said ‘North Pole’ and had Christmas greetings to his parents. They told us that the elf had remained on display in their house all year. The school

also gave them photos of their child helping to make a Christmas Bauble which was used in the school Christmas play. They now have this bauble which sits in front of their fireplace. These parents commented that their child had **"re-engineered Christmas for us – simple can still be fantastic..... Every day that we got up and that he got up in the morning was a day to celebrate. Every day was Christmas or New Year. When your child has a terminal illness you need to live in the moment"**. Giving a gift of a small box of chocolates to one of the people selling The Big Issue and bringing some joy to his day is what life should be about. This is what he has learned from his son.

Two of the parents told us of the heart-break of returning to their homes with a Christmas tree set up with gifts for a child who was always supposed to come home. For both of these families they had not anticipated that their child would not come out of hospital. **"He went into hospital on 19th December for monitoring after his immunisations. His condition was not meant to be terminal. He was always coming home for Christmas.....We came home after he died to presents under the tree for him. I grabbed them and shoved**

them in the first cupboard I could find so I didn't have to see them". Another parent who also came home after her child had died to a house decorated for Christmas found she couldn't bear to see the reminders of Christmas and confront the expectations of having a new baby to celebrate Christmas with. Her parents and in-laws packed all this up for her.

Many of the parents in the group talked about the difficulty of buying presents for other children, not only for Christmas but also for other occasions such as birthdays. **"I was in tears buying presents for others when I want to be buying things for our child. We have to stop buying things that he will never wear"**. One parent told us that for the first Christmas she made photobooks and a bauble with her child's photo on it for her family. It is heart breaking watching other children opening presents when your child is not there to open presents also.

A parent told us of her experience on the first Christmas without her child as she was watching her nieces and nephews receive and open their Christmas presents. **"That first Christmas no one**



bought presents for our child. I felt he was so excluded. Watching the other children open their presents I felt like I was being eaten alive. It felt like a knife in my soul. We want people to still buy presents for him. It was just such a reminder that he wasn't there". It was sometime later in a moment of great grief and anger that she told her parents how hurt she was that there were no presents for him. Since that time there have always been presents for their child at Christmas. She said **"They just needed me to tell them what I wanted. You expect other people to know what you want when you really don't even know yourself".**



Other parents also talked about the need to let people know what you need but also the difficulty of knowing what you need yourself. One parent told us how she told her mother that she could not spend Christmas Day with her if the 2 little grandchildren were going to be there. **"Somehow my mum engineered it so they weren't there. I still don't know how she did that as I think it was their turn to spend Christmas with our family, but I just knew I couldn't be there if they were".**

We talked about ways that people can bring their child into Christmas with them. It was acknowledged that these rituals and customs develop and evolve over time. One parent has a candle for her child that she or someone else light each year and that sits on the table as a reminder that the child is part of the family always and is with them. This year the candle will be not only for this child but for 2 of his great grandparents who have also passed away. Another parent also has a candle they light for Christmas but she also has a Christmas poem or prayer that one of the children reads out, or herself if she's feeling up to it, each year for her son. Some of the other parents present in the group had

not experienced many Christmases without their child and appreciated hearing about rituals others use. We also heard about a tradition of including a chair or setting a place at the table for the child. We were told that there is someone who makes little chairs for people to have to place in memory of their child or other family member.

One parent talked about how much relationships changed in the first 12 months after their child died. **"In the first 12 months the whole dynamic**

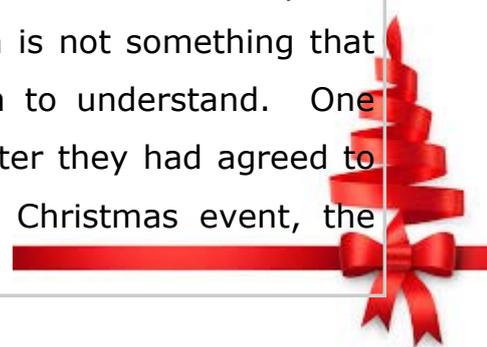
changed, because some 'got it' and others didn't. People acted weird, even family, and they made us feel like we had done something wrong. People either stepped up and we still have strong relationships with some of these people, or we lost friends".

Most grieving parents share this experience – the experience of the people who do step up not necessarily being the ones you would have expected to. It is hard to know how to act during this season. A parent in the group said people need to be in it for the long haul. If you reject invitations this year will you get those invitations next year and the year after that until you may one year be ready to accept, or do people give up on you?

A few of the parents had the experience of one side of the family being more sensitive to their needs than the other. One parent told us that her side of the family appeared to be quite sensitive and understanding of how they may be feeling but her husband's side of the family continued to behave as if nothing had changed at all. One of the other parents shared a similar experience but then said that as time went on and the rawness of the grief lessened she realised that her family lived close by

and saw them regularly. **"They could see how we were and how we were coping on a daily basis. The other side of the family lived several hours away so didn't see us so they didn't know how we were managing. I used to avoid answering the phone when they rang".** If people are there they can see signs of how you are coping, for example if you have Christmas decorations in your house. Now, with the benefit of time and hindsight she can see that it was hard for the other family to know how to behave towards them.

Some of the parents spoke of the many decisions they had to make in the hospital in the final days of their child's life. **"We had to make so many decisions – what treatment, how far to go, to turn off life support".** The parents in the group agreed that it is now very difficult to make any decisions. One parent told us that 10 years on she still can't make decisions – even small decisions about which supermarket to shop at that week. Your confidence in your ability to make good decisions seems to disappear. The effort required to make a decision is not something that other people seem to understand. One parent said that after they had agreed to go to a particular Christmas event, the





people who had organised it cancelled. They could never understand the significant impact that had after all the angst that had gone into the decision to attend. **“Before you make a decision you consider what could go wrong, what are the risks of the situation, is there a way out, what is your emotional state”**. No decision is made lightly. The importance of having an escape route was discussed and it was agreed that it is always important to have a way out and even to be able to change your mind at the last minute. A couple who had decided to attend their son’s school Christmas play were dismayed when their escape route was cut off by the musicians just when they decided they really needed to go. Another parent told us how she had changed her mind at the last minute and decided she did want to go to her sister’s for breakfast to watch the children open their presents when she had told her she was not able to come.

There was also discussion about New Year. Some people said that for them the next year begins on the date their

child died and the New Year, 1st January is not significant for them. **“The year resets at anniversaries”** Others said they find New Year very difficult as another year ticks over and it is a reminder that yet another year has passed without your child with you. **“With the New Year you are leaving him behind and the gaps just get bigger and bigger”**.

The biggest fear of every parent is that his or her child will be forgotten. It is very hurtful when the child is not acknowledged on Christmas cards, in gift buying and giving, when their birthdays are forgotten and when people seem to go on with their lives as if nothing has changed and expect you to do that also. It is therefore really special when other people do show they remember, particularly when they are not the people you would expect. One parent told us how a colleague who was a friend of her mother’s asked her how she was as she was aware that her child’s birthday was coming up and she knew how old he would be turning. The parent commented **“For someone else to say out of the blue ‘how are you going’ and remember his birthday is coming up is really important”**.

Parents tonight shared many ideas and experiences of surviving Christmas in the

years after their child's death. Some things were themes that feel like they are of particular importance:

- ★ Always try to have an escape route and try to explain this to others if you can. Let them know you will try to come but may need to leave early without saying good bye or you may need time out.
- ★ Try not to make too many firm commitments – allow space for last minute change of mind
- ★ Understand that it is difficult to make decisions so you may not be able to tell people what you want or need
- ★ Understand that other people often do not know what you want or how to behave so any guidance you can give them may be helpful eg – I want you to acknowledge my child when you send me a card, I want you to have a gift for my child under the tree.
- ★ It is OK to just let Christmas go by without getting caught up in the commercialism or the 'happy family' celebrations.
- ★ Develop practices or rituals to keep your child's presence felt in your Christmas – allow these to evolve over time.
- ★ Remember it is not only Christmas that may be hard, for some New Year is also very difficult and of course there

may be other significant days around this time – birthdays, anniversaries etc.

- ★ Be gentle on yourselves and don't try to push yourselves too hard.

We would like to thank all the people who came to the group for sharing their wisdom and experiences and allowing us to share these with all the readers of the newsletter.

All who have been involved in the family bereavement support group and the production of the newsletters this year wish you and your families a peaceful festive season and hope you are comforted by the memories of your child and by the love you have for your child and the gifts your child was able to bring to you in his or her lifetime, however brief.



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.****

PLEASE NOTE THERE WILL NOT BE A GROUP HELD IN JANUARY

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

**Thursday 15th February, 2018
7:30 pm – 9:00 pm
The RCH Foundation Board Room
Level 2, 48 Flemington Road
Parkville, VIC 3052**

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 Amber Leuders for scribing parents' statements.
Also to the RCH Volunteers for mailing assistance & to Carly Blanche for ensuring
the newsletter is typed, formatted, collated and distributed to interested people.*

Social Work Department, RCH

