

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER DECEMBER 2019



Welcome to the December 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.

“The Empty Chair: Grief and Celebrations”

This was the last group of the year and with Hanukkah, Christmas, New Year, holidays and many other celebratory events expected in the coming weeks, the group provided a space for people to stop and reflect on the past weeks, months and in some cases years and to talk about their grief as 2020 approaches. The discussion in the group was not entirely as would be expected at this time of year with little direct reference to cultural celebrations, New Year and family expectations at this time of year, but lots of discussion about memories, relationships and the passing of time. If the parents wished, they could partic-



ipate in a creative activity while we talked. A glass jar, a candle, a ribbon and paints were provided and parents were invited to decorate the jar, tie a ribbon around the top and put a candle inside as a light to remember their child.

A family who do not celebrate Christmas as they are Jewish, although their children are very aware of Christmas celebrations and gifts, told us that last year they went to the seaside at Christmas time, knowing this was likely to be their son's last Christmas. On Christmas Day they visited a friend who celebrates Christmas and their son was able to get close to and sniff prawns and ham –

foods that are not kosher. They had taken photos to send to grandad. This year the other children are asking if they are going to do that again. **“Everything we started to do in that year for our son has become a family tradition. We haven’t celebrated Halloween before but we did last year because it was becoming a bit of a thing in our street so now it has become a tradition”**. Actions and events take on a special and lasting significance when it is the last time your child will be able to participate.

Continuing the theme of memories and reminders of your child, a parent in the group whose young child had died suddenly in a tragic accident almost 2 years ago told us that: **“90% of the shock has worn off – sometimes I gasp when I remember that this is real”**. Another parent who has been without her child for much longer said **“There are times when I think, ‘did this even happen’? Is this someone else’s nightmare that I fell into”?** What is lost when a child dies is not just the physical presence of that child but the changing relationship that you and your other children would have had with that child as they grew.

One parent said **“I miss being a parent of a child that age, and seeing him age. I miss seeing his school friends”**. Another parent said **“I don’t know what it’s like to be a mother of a 4 year old”**. For one parent, knowing that her child who had only lived for 6

weeks would now be turning 10 was very challenging and she was finding this time more difficult than she had in recent years.

Some of the parents in the group had other children and they talked about keeping the child’s memory alive by talking to the siblings about him or her. A parent commented that their other child who was only 9 months old when his brother died will know his sibling through them. Another parent also said that the children who were born subsequent to their older brother’s death just know him as part of the family. He is always part of the family and frequently talked about. One parent wondered if they talk to their other children about their sibling too much. The group assured her that this was unlikely. As the younger children reach the age of the child who died feelings can be difficult. One parent said **“Someone asked me if it makes me feel better now that my younger child is approaching the age his brother was when he died. It doesn’t feel good at all. Do you think I don’t worry that something will happen to him too? Accidents happen”**.

The passing of time, the approach of 2020 and the impact of this on memories was distressing for many parents. One parent commented that 2020 seems such a significant number. She explained that when her child was born in 2015, 2020 seemed like an impossibly long time away and now it is almost here. She said

“The year 2020 from 2015 feels like craziness, but now it’s here. I’m feeling worse, feeling sick. It feels like a long time since I heard his voice, saw his smile, changed his nappy. It’s overwhelming”. For another parent 2020 was significant as it is a decade since her son was born – **“We are 10 years down the track. Ten years has really hit me. I think 2020 is hard because he was last here in 2010.**



The passage of time impacts on memories. Some of the parents who knew their child had a limited time to live, consciously tried to create and embed memories of their child through experiences and photos. One parent said she made sure she took photos of her child every day of his life. Another father said; **“I remember there were times when we were lying in bed together. I used to think- ‘savour this moment’. I remember telling myself that, but I can’t go back to what it felt**

like in the moment”. Another parent responded that some memories are so intense it hurts **“I hate how sometimes a memory can be so imbedded in you, so intense that even your fingertips hurt, but another time it can feel so far away and there are things you don’t remember”.**

Parents commented on how the photos are all memories and bring back those times, but what about all those moments that were not captured in photos? Many of the parents in the group felt that their memories had faded or changed in intensity as time had passed. It was also apparent that the intensity of memories maybe different at different times.

Creating a memory book was something a parent in the group was doing after a friend had suggested it. This is a way to capture the memories of others who knew your child as well as prompting many memories of your own. She sent emails to a whole lot of people asking them to send some memories of her son. While reminders often had to be sent she received many thoughtful replies. She told us that one day she will collate them all into a beautiful memory book but she is not ready to do this just yet.

Whether you want it to or not, however, life continues and memories will not remain unchanged. This is part of the grief and the experience of ongoing loss for many parents.

Another loss that parents in the group discussed was the loss of relationships

when those you thought would be the most supportive just stepped back and others you did not have any expectations of stepped up. Over time text messages drop off and even those who seemed to be at least making an effort disappear or fade away. A couple whose child had been born with a number of difficulties and had lived almost to his third birthday, well beyond his predicted lifespan due to the care and commitment of his parents shared their experience with us. They told us how they would see other families in the hospital with lots of extended family around all the time but their family were not there. They felt that their families did not want to be around the family that lost their kid. **“There were people who seemed like they would be there, but when you needed them they stepped back into the shadows”**. As they knew their child would not have a long life they had a ‘living funeral’ at the zoo where people could come and celebrate with them and say goodbye to their child while he was still alive. When he did die they didn’t want to have a funeral but wanted to highlight the happy memories with close family and friends so invited special people to the zoo again. Sadly they felt very let down by one family in particular who were angry about the fact that this took place on this cousin’s 21st birthday. This experience of people putting their own interests above the needs of the grieving family was not unique to this family. We also heard of ‘friends’ who priori-

tised their house warming celebrations over an opportunity to say goodbye to their friend’s baby, of a relative who was clearly uncomfortable allowing the grieving parents to hold her baby and of many other situations when friends or family appeared to have been unable or unwilling to even try to be supportive.



One parent commented that anger with such people interfered with his grieving. He said: **“I was plagued in my ability to grieve because I focused on my anger towards the people who couldn’t be there for us”**. This parent went on to say **“I’ve kept the axe sharp. Every relationship needs to be mutually beneficial. Whether it’s a lawnmower or a human, if it’s not beneficial then it needs to go”**. Some parents said that they sometimes felt that these friends and family did not step up because of something they were

doing, but over time they realised the problem lay with the other, not with them. A father commented: **“We are strong as a unit. We only need our kids and each other. It’s up to them, not us. Acquaintances often step up more than friends”**. Another parent commented, **“The same people are with me, but I’ve lost some of my closest friends. She just didn’t know how, and it broke my heart, ‘cause I’ve known her the longest. I just thought she’d try”**. Most parents understood that it is difficult knowing how to be there for a grieving parent but they appreciated those people who at least tried, even if they didn’t always get it right. They acknowledged that this took courage and appreciated the efforts of people who were not afraid to try. Feelings about those who were not there were mixed. Some felt it was just too hard for them, others that they were just ‘dumb’ or that they were weak and could not find the courage to be there. We heard of one situation when friends did not come to see the child for the last time but a few weeks later invited the mother for pizza and beer. **“You couldn’t believe how f..... dumb they were. It’s not like one of those things where people don’t know what to say. Did they think a pizza and a beer was going to chill me out”?**

Parents found it very hurtful when other people would not talk about

their child, even when the parents brought his name into the conversation. One couple had friends stay with them for a week and not once mention their child’s name. They said it was like these friends just wanted to be positive all the time, it felt like a self-help group. Everything always seemed to go right for these people and they had no idea how to behave when there was such sadness. This couple find it frustrating when others say that being in their shoes is their worst nightmare. They said **“Don’t they realise how truly awesome our child was”?** Some people seem to forget the big smiles, the cheeky personalities and the wonderful person the child actually was and that having that child, even for a short time was also a blessing.

Not all parents in the group felt they experienced this loss of those they had been close to. One couple said the experience was different for them and they found friends and family very supportive. They said **“I feel like most of our friends, if we said give us a hand, I can’t think of anyone who wouldn’t go out of their way to help”**. They have also experienced unexpected support as well with a neighbour who had previously not been very social inviting them to dinner just after the daughter’s birthday. Another parent commented on a family who had always been a great support, very sensitive and aware of times that may be difficult and always being so

thoughtful. She said, **“If you asked me when my child died who that family would be, they wouldn’t have been near the top of my list. They weren’t parents but they had the courage to keep checking in”**. This parent has also experienced some friends who have tried to apologise and repair relationships. **“We were the first people in our group to have children. We did have people contact us after they had their first child and say they didn’t step up. They knew it was big (losing a child) but they didn’t realise how big until they had a child of their own. That takes a lot of courage to say we were not as supportive as we could have been. In some ways it has repaired the friendship”**.

It was also felt that men are not as good at talking about feelings and difficult things as women and that it is more difficult to get real support from men. Occasionally however, even with men someone will ask how you are and really mean it.

A parent asked – **“do we really look sad all the time”**. Another said **“I have become the ‘bereaved parent’ in the group.”** Sometimes it feels as if other people are afraid to come too close, like tragedy is catching. As well as the sadness some parents commented on how tired they were and

everyone in the group could identify with this – grief is exhausting. A parent spoke of how hard it is to allow yourself to just be in the moment and how they wonder if they will ever be able to be really happy again. A parent commented on how empty her life is now **“Before I was always busy, always had something to do. Now I wake up each day and I do nothing, absolutely nothing”**.

In response to the question about happiness, a parent responded that they had promised their baby that they would keep living their lives and would be happy. She said at first it had been a conscious effort and was difficult but gradually it had become more natural and now they could be happy and really enjoy their lives. She said, **“Don’t think about what it should have been like, enjoy it in the moment. But there are still absolutely moments when it is still really shitty”**. She said, **“The hardest times are the birthdays of his siblings. Other times are difficult, like his birthday but the siblings birthdays are the hardest”**.

At the end of the group some people told us about what they had painted on their jars – stars, flowers and butterflies, a heart with a piece missing, a sun. Some of the parents planned to put the jar and candle on their child’s grave.

As always, many thanks to the parents in the group for allowing us to share their thoughts, experiences and stories with others through the newsletter. For many grieving parents this is a particularly difficult time of year. The celebrations, family expectations, even expectations from living children and the turning of the year – another year passing, can be extremely difficult to navigate. The anticipation of these events can be more stressful than the events themselves. Many will have navigated this season before and created rituals or strategies to get them through but for others it may still be

new and uncharted. Try to allow yourselves some time and space for your grief, have contingency plans if things do not go as you had hoped and be gentle with yourself and those in your life who may be trying to help but may miss the mark. May you all move through this season, bringing your child with you and find friends or family who can travel the journey alongside you.



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:

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 20 February 2020
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 from what could have been, to what is - adjusting to life
without your child**

Please Join us in February 2020

*The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating the group discussion and
writing the newsletter. Thank you to
Kelly O'Mara for scribing parents' statements.
Also to Marina Puljic for ensuring the
newsletter is typed, formatted, collated and distributed
to interested people.*

