

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER SEPTEMBER 2019



Welcome to the September 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 Impact of Grief on Communication”

The theme for this group was communication – how grief changes how we communicate and what we communicate as well as the way others communicate with us. This was a broad but very rich topic as people in the group discussed how they navigated the challenges of communication about their grief and their journey.

As the group members introduced themselves it became apparent that many were experiencing some particularly significant times. One parent told us that it was just 18 months that she had been without her child. **“I think 18 months was harder than the year, it is half his life”**. Another parent is approaching the 10 year anniversary of her child's death and said she struggles to comprehend that he has been gone for that long. For another couple



August and September contain significant dates as their child was born in September and lived until the following August. A parent attending the group for the first time told us that they had just had a service for their babies who passed away only 6 weeks ago. We noted that different days and dates have different significance for different people and that these times can take you by surprise with the intensity of emotion they evoke.

As the group began to talk about communication one parent said: **“At the beginning I found lots of adjectives, but now I'm just sad”**. Other parents said they had words to describe how they feel but that other people don't seem to be able to understand – **“It's still that battle of people understanding how bad it is. You can't get them to see how**

you're feeling inside". People in the group felt there are different levels of understanding. It is harder for people who do not have children to understand just how intense grief is. A parent said **"People who have kids that try to put themselves in it, but they don't understand the level".** Some parents in the group said they would not want anyone else to truly understand, as the only way to understand is to have lost a child yourself and they wouldn't wish that on anyone. One parent in the group said; **"I understand your loss because we have all experienced that loss, but I don't understand your journey as everyone's journey is different".** Many in the group said they feel that the group is the only place where people do understand.

When parents reflected on the words they use to describe how they feel a number said they feel angry. Anger, blame, hate, agitation were all feelings that several of the parents expressed feeling at some time. For some, anger in particular is a feeling they have a lot. For most anger was not directed at one particular person or event. One mother said: **"I'm angry because it was just a sliding doors moment. I'm just angry at the world. He was here and sometimes I'm made to feel like he wasn't".** Another parent reflecting on her journey said: **"I didn't realise how far I'd come when I was, like**



wow, I haven't yelled in a week". One parent said she did not feel angry and wondered when this would come. Another said that his psychologist told him that anger and sadness are just 2 sides of the same coin – **"My partner feels angry, I feel sad, we are feeling the same but expressing it differently".** Grief is not linear with a set number of emotions you can expect to experience, grief is much more messy than that and not everyone will feel the same emotions.

One parent in the group reflected on how she has changed over the 3 years since her son died. She said that there was only a small gathering for her son's birthday this year and instead of being angry she accepted it. **"I could just focus on him, I wasn't focusing on who wasn't there. I could be more in the moment. I didn't have to worry that someone would say something that**

would make me angry. I feel lighter.....I felt like I had to prove to people that I was a mum and I know what it is like to be a mum. Now I think I don't have to prove it to anyone, I know I am that person, I am a mum". Parents talked about how it is important to let yourself feel the emotion you are experiencing at the time. Sometimes that can be a dark feeling and sometimes it is lighter. One parent said **"I have to feel what I am experiencing. Sometimes I can**

giggle now, yes, sometimes I really do that”.

A few parents told us that they had made a conscious decision to move away from their anger and to seek happiness. **“I was feeling hate, anger, pain and despair. I had to make a decision not to live in darkness. It was like I was living in a dark house and every time a little chink of light came in I closed it out. I told my wife I couldn’t stay in this dark place and we walked through the grief house together and out. We made the decision to let in the light. We love life but we carry the sadness forever”.** Another parent also talked about making a conscious decision to live life and be happy. She told us how they promised their son they would keep on living and be happy and while it has not always been easy they have been able to do this and bring him with them. A parent said: **“The way I communicate now is about happiness because the alternative was too hard”.** Another parent expressed a similar sentiment when she said she couldn’t keep being angry – it is too exhausting.

It was very important to the parents in the group that they could talk about their child and that others would talk to them about their child. When other people refuse to talk about

the child it can feel like they are denying that the child ever lived.

A few parents told us that they had spoken at their child’s funeral or service and told people they wanted them to keep talking about their child. Some friends really appreciated being told what the grieving parents needed as they did not know how to communicate with them. A father told us he is surprised how easily he can talk about his daughter. He said he thought **“Wouldn’t it be easier to say, no, I don’t have children, but it is a way to acknowledge her and it would be much harder to deny she existed”.** Some parents said they have learned to be very honest with others and not to care how it makes them feel. **“He is part of my identity. Of course people are going to feel bad, but I don’t care about that”.** Another parent said **“I’ve never been so blunt or honest. I don’t care how uncomfortable it makes them. We wanted to let them know we want to talk about them every day and every minute and we gave them permission”.** One mother told us that her friends followed their lead – **“we spoke about him all the time so they did”.**

A mother told us that she found her friends and family were hiding their own joyful events from them, especially pregnancies. She



decided to be very honest with them and told them not to hide anything from them- **"We're still the same people....just not"**. Another parent told us that she was just the opposite; she did not want anyone to smile or be happy around her or to tell her about pregnancies. She told us about an experience she had when shopping - she heard a baby cry and she hid and **"balled my eyes out"**.

There was discussion in the group of the grief of losing friends after the loss of your child. Some seem to disappear while others may unexpectedly step up. Friendship groups can change significantly over time. This process is complicated when the ones who are not stepping up are family members. When a child has had a short life or a difficult illness, it may be those who travelled the journey with you who are most able to understand what you need afterwards. One parent said **"Quality, not quantity"**. It can also be that family relationships are more complicated than friendships. A mother told us about her experience with her father **"I am so close with my dad, but he just cannot talk to me about my son. We can talk about anything except him. I talked to my mum about it and she said 'he can't fix it'.....he's there and he's present, but he can't talk to me about him. He won't shut the kids down about him, just me"**. When this parent shared this story, another mother said that she could have been telling her story - **"My dad's the same - I think he thinks if he breaks, I'll break.....I've accepted that I'm not going to get the verbal conversation, he'll just**

come and give me a hug". A parent in the group acknowledged that it is hard for grandparents as they grieve for both their child and their grandchild.

There was some discussion about the other ways people offer support and care when they may not be able to talk about the feelings. Sometimes a hug or a look can mean as much as a conversation. Some people show their care by dropping food around. A parent told us how she sees people at her son's grave. Initially she felt uncomfortable about this as she considered this a very personal space but now she sees people are visiting him, even when they can't visit her and she is pleased that these people are acknowledging her beautiful son.

Communicating with young siblings who do not have sophisticated language skills and paying attention to what they are communicating to you is also important. One parent has her child's ashes in a special teddy bear. Her young son relates to this bear in different ways depending on his mood, sometimes playing with it and at other times just cuddling it quietly. Other parents also spoke of their determination to be happy, 'normal' parents for their other children. One father said he didn't want his son to grow up hating his brother for making his parents sad, angry people. Other parents also spoke of how the other children 'keep them going'.

How the loss of a child impacts on what parents feel about themselves also came up in the group. One parent told us **"I want to help others, because I can't help me"**.

Losing a child can challenge your beliefs about yourself and your self-worth. Sometimes you need to tell yourself that you are a good a worthwhile person, even if your child has died.

Discussion in the group on this evening clearly showed that navigating grief is complicated and exhausting and that it changes over time. A parent explained to the group her feeling that as a grieving parent you have to adapt yourself to other people and their grieving styles all the time and this is exhausting. She explained that in life there are always people you click with and others you feel are very different to you, you come across all these types in your grief and you constantly have to adjust your reactions to them. Sometimes it feels like you need to put on a façade to navigate the world.

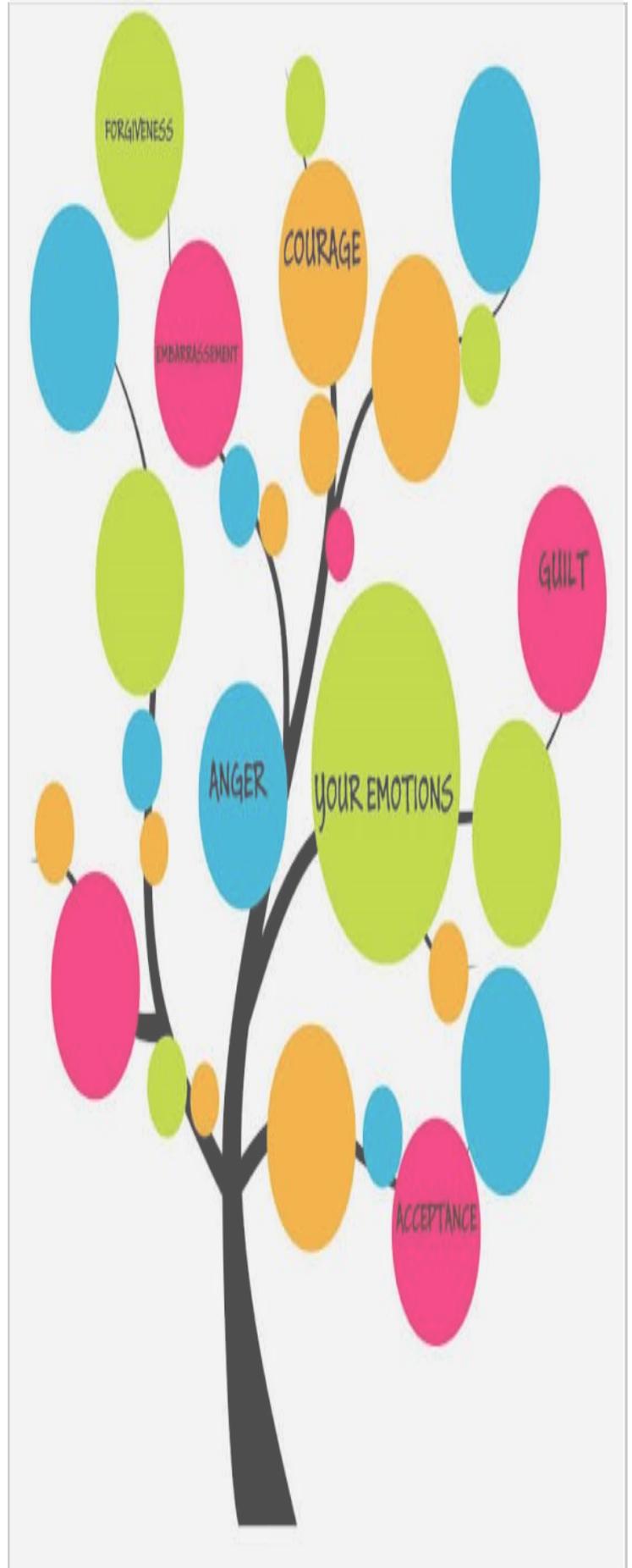
Some parents said they have learned not to worry about how others react to their grief but they also spoke of how insensitive or ignorant reactions of others are deeply upsetting and can make them very angry. One father commented that his child's death **"exposed how much people are terrified of death, especially the trauma of a child's death"**. Some parents can appreciate it when others try be sensitive, even when they miss the mark. Another parent commented;



"it's incredible that they're comfortable with being uncomfortable". Over time some parents have been able to accept that they will get something from some people but not from other people. A parent said **"They just want us to be okay"**, and another said **"they're not bad people, they just can't help me on my journey"**.

Communicating about your grief is difficult. On the one hand the people in the group expressed the wish that other people understood their grief better but they also said they would not want other people to truly know what it felt like to lose a child. Telling people what you need can be hard at times but can also help others know what you want them to do and say. One parent said it is not helpful for people to tell them 'I've been thinking about you' - **"how do I know they have been thinking about me. It is nice when people just send a random text message"**. Most importantly grieving parents want to talk about their child and to hear their child spoken about and their lives acknowledged and valued. Some parents in the group said they have been able to let go of some of their anger and resentment and feel a bit lighter, more able to experience happiness and to be in touch with the love their child brings to them.

I would like to thank the parents who attended the September group for their openness about the challenges of communication when you are grieving, for sharing their Experiences and for their Sensitivity to the different journeys of all those present in the group.





IMPORTANT

The Parent Bereavement Newsletter
is going digital

From October 2019 we will be sending newsletters via email each month. Many readers have already been receiving the newsletter this way, but for others we realise this may be a big change.

Please let us know your email address if we do not already have it, and if the change raises difficulties for you.

please contact Marina Puljic via email:

Bereavement.Services@rch.org.au

or

Helen Stewart/Robyn Clark

by phone on 9345 6111.

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 17th October 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:

Rituals that support grief

The October group will be led by Paul Hammat, head of Pastoral Care Services.

Please Join us in October

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

