

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER June 2019



Welcome to the June 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.

"Thinking about feeling – how do we process intense emotions?"

A large and varied group of parents gathered together to share their experiences of living as a bereaved parent. There were very recently bereaved parents attending the group for the first time, as well as parents who had lived with their grief for longer. There were a number of parents in the group whose child had been healthy and died suddenly and unexpectedly and others whose child had a serious illness and their death was anticipated, sometimes for weeks and sometimes much longer.

One parent whose child died 15 months ago told us that she was finding the second year almost harder than the first year. She told us she could barely remember the first year and how she got through each day. She said **"We have a son who is now 2 years old. He gets me up every day"**.

The topic for the evening was thinking about feelings and how to manage the sometimes overwhelming emotions that grieving parents feel – grief, anger, guilt and many more.



One parent told us that she copes by getting up each day and going to the cemetery. She said **"How do I get up, how do I do it? I go to the cemetery daily. It is my way of still coping, even 3 years on. It is the only thing that gets me out of bed but it can still take me ¾ of an hour to get dressed. I find myself just sitting there with no purpose.....If I had nothing to do I may not be able to get out of bed"**. She told us that in the early days immediately after the funeral she and her partner got up early and dressed and went straight to the cemetery to be with their baby – **"It was just like getting up and going to the hospital which we had been doing every day for most of his life – I lost that routine when he passed away"**.

Another parent said she also goes to the cemetery each day and takes her other child with her. She told us that her child's resting place is very bright and she makes sure it always looks beautiful. As there are no other children in that part of the cemetery her child's resting place really stands out and people comment on how

beautiful it is. Keeping this place looking like it does, an inviting vibrant place to be, particularly for children also gives this mother purpose.

There was quite a lot of discussion about surviving, particularly in the early days and a number of parents said the only thing that kept them going was having a routine. A parent described the early days to us **"I don't remember much of the early days – I woke up, an hour would pass then another and another and another then the day would end and I could go back to bed and sleep and the next day would be exactly the same"**. Routine and repetition seemed to get many parents through the early days and the ongoing bad days.

Other parents also talked of finding a purpose or of finding some meaning in the death that could help them to keep going. Some parents talked of spirituality and beliefs about life after death. One parent said she had to believe in an afterlife to enable her to cope and keep going. Another parent said he believed in fate and that the sudden death of his healthy child was fated. He said his daughter's death was so unexpected that he kept asking 'why did this happen' – **"I could find no blame of guilt on anyone.....this has changed the order of life.....children are supposed to live longer than their parents. I thought 'this is fate' and I am looking to my spirituality. All the things that were important to me before – money, my job, these things do not matter any more"**. Several other parents in the group also believed in fate but there were others who did not and spoke of life being like sliding doors* where seemingly insignificant or chance decisions or interruptions could lead to very different outcomes. Some parents spoke about constantly

asking themselves 'if I....' or 'what if...'
"Every day can be "what if" moments. He was ripped away from me, he was meant to be with me". Another parent responded **"Everyone asks the 'why did it happen to me' question but there is no real point in asking as there is no real answer. I try not to think about why as it can be torture, but more, what can I do today to get up"**. Someone in the group said **"It is just the worse luck in the world. You never think this will happen to you, it just happens to other people"**. Another parent said a friend recommended she go to a medium when she was trying to explore spirituality. She was amazed that the medium could tell her things about her child that she could not possibly have guessed. **"I knew that my child is still with me and that helped me to manage my feelings"**. One parent said **"I don't understand what happened, every single day I don't understand and I don't want to see a future without her, I never want this pain to be any less. I have no purpose, nothing else mattered.....I don't want to think about 2, 3 years down the line....I don't want a purpose"**. Other parents related to this feeling and said they had also felt like this at times but one said **"I just have to think about what I need to do to get up today"**.

A parent who has lived with the loss of her first child for 91/2 years said that she is astonished that she has managed to live without him for so long. **"Only a couple of months after he had passed I met a woman whose child had died over 30 years ago and I couldn't believe that she had lived with that grief for so long. I could barely get through each day and I thought 'it has only been 8 weeks, how does she do it'. Now it is nearly 10 years and I can't believe it has been that long"**. She went on to tell us how certain points in time take on a

symbolic meaning and can cause the grief to be intensified for a while. Like some other parents in the group she had found the birth of her second child was a lifeline for her. When he started school she found herself unexpectedly back in a place of intense grief and she went back to counselling for a while to understand this. **"I don't think I realised how much I relied on my son to help me cope with the grief of losing his older brother. When he started school it was like I was handing him over into the care of someone else like I had done with my first child when he was admitted to hospital. It doesn't feel the same with my daughter – I can't wait for her to start school"**. She also acknowledged that the 10 year anniversary which is coming up already feels very hard. Another parent commented that when she first started coming to the group and met this parent and others who had lived with the loss of their children for a longer period of time, she also could not imagine living that long without her child and now it was almost 3 years. Other parents, particularly those who were recently bereaved echoed these feelings of not being able to imagine living with these feelings for so long. Some parents commented on how much they hate it when other people ask them 'how do you do it' – **"You have no choice, you are forced to do it"**. One parent said she has considered killing herself but said it was the knowledge of how this would impact on her other child, her husband and all the other people who loved her that had stopped her doing it. Other parents also said they had wished or did wish they had died with their child and had also thought about taking their own lives.

The profound impact of the death of a child on your own sense of who you are was raised by one of the parents in the group. She said about the second year **"This year I am grieving the loss of**

myself as well – I pray that I can laugh and smile like my old self.....I went from being a high functioning person to just sitting on the floor". She went on to say that she believes that when you lose a child you lose yourself as well because that child is part of you in a way that another adult is not. She said **"I still mother a deceased child and a living child"**. Other parents echoed this sentiment and spoke of how they feel their child still with them. One mother whose child died more than 10 years ago said **"He is still in the house with us – I feel him all the time"**. Another father



said that he believes his daughter's spirit is still with them. His wife said that their daughter had come to her in dreams and when she asked her if she was okay the child said she was and that she wanted her mother to be happy. Another parent has butterflies in the house as her baby only lived in the butterfly ward at the hospital and she now associates butterflies with the memory of her child. Some parents in the group told us that they have been asked by others how they bear to have photos and other reminders of their child around the house. One parent told us how a friend who had unexpectedly lost a much loved dog told her how she had put her pet's ashes in a cupboard. She looked at her friend and asked **"What are**

you saying? Do you think I should just put my child away in a cupboard”? People need different things when they grieve and their choices should always be respected no matter how uncomfortable they may make others feel.

One parent said **“I wonder if we ever had a sibling would we make them talk about him. I feel I would encourage them to talk about him all the time. It would mean that I did not have to always be the one mentioning his name”**. Other parents shared their experiences of talking about their child and of other children talking about their brother or sister. Some people had experiences of other people crying when the name of the child was mentioned and they then felt they had to comfort the other person. A parent said **“I don’t want people to cry when I talk about him, I want to celebrate his life”**. Other reactions included people clearly being uncomfortable and wanting to shut down the conversation. One mother told us of her experience of being with friends and being able to cuddle their healthy newborn. She was acutely aware of her friends’ discomfort when her child (2 years old) kept referring the baby by his own deceased sibling’s name. Some people give clear messages that they do not want to talk about the child at all. Several people in the group shared stories of how they had witnessed their children talking to other children or even other adults about their deceased sibling in a very matter of fact way without the complication of adult emotions. One parent told us that when her son started kinder he made a particular friend and when he told him his brother was in heaven this child also said he had a sibling in heaven. This information was exchanged between the two children as simply facts about their lives. Another parent said her child told another child that he had a brother in heaven and a sister at home. The other child told him

about his sibling situation and they continued to play. A parent commented **“Children are honest”**. One parent told us that when her son talks about his baby sibling **“that can bring a whole range of emotions, more so than with family and friends – it can touch deeper when other children talk about it....but then he runs off and plays”**. Parents also talked of how they talk about death to their living children. One parent is writing a little book for her child where she describes death as like a cocoon from which a butterfly emerges. The butterfly is the spirit and the cocoon is just a lifeless shell once the butterfly emerges. She has told her child that his brother is **“wherever you want him to be. Sometimes when he sees stars his says his brother is there and sometimes he says he is a butterfly”**. Parents mentioned some books they had found helpful – The Invisible String and Beginnings and Endings with Lifetimes In-between.**

A couple whose child died after a year of being unwell with cancer said, although their child had died very recently they had been grieving since he was diagnosed and they knew how aggressive the cancer was. His mother spoke of the losses they grieved over that year – **“After his surgery he had a hemiplegia and walked with a limp and I thought ‘he will never be able to run again’. He attended school for a few hours most days but one day when I was picking his sister up at the end of the day I thought ‘I will never pick him up from school at the end of the day again’**.

A father talked about being busy and being distracted as important to him to help him get through each day. He said he has returned to work and has found work gives him a reprieve from his grief. He wondered if this is okay, not to think about his child constantly. Another parent told us that she had been through

some very difficult times after her child had died and had contemplated killing herself. She now cares for a quadriplegic man and she said **"I love my job, I love caring for him. I need to do everything for him....I look forward to my work every day"**. She said you need to find something that makes you happy. Another parent told us that a friend had taught her how to make sourdough bread when she was in the depths of her grief. She said she now loves making the bread. **"It is a long process and you have to mix it and punch it and I love making it. Now I supply sourdough to a few café's. I have to get up at 5am to start getting it ready – I think I am a little bit mad but it gets me through and I enjoy it"**. Having something purposeful that you enjoy doing does not guarantee that the grief will not still overwhelm you at times. A parent said that she can still cry for days. Another parent told us that she tries to set goals for herself to help her feel some purpose or motivation to keep moving forward. She said she sets goals that are often unachievable and then she feels let down when they are not achieved. Some of these goals depend on the cooperation and sensitivity of other people and she feels she is constantly let down. This issue resonated with several others in the group and parents talked about how often those you expected would be there for you just disappear and others had unexpectedly stepped up. Old friendships were let go and new, stronger friendships were formed.

Often parents may grieve differently from each other – One father told us – **"We were told to grieve together but that is not the case, we are grieving very differently"**. A mother told us that she grieves very differently from her partner and that his grieving is

destructive for her. Recently she has begun to talk to him about it and things have improved a little. Yet another parent told us that although she and her husband grieve differently **"there is only one other person in the world who knows how it feels to be the parent of the child we lost and that is my husband. My sister knows how it feels to lose a nephew and my parents know how it feels to lose a grandchild but only we know how it feels to lose a child"**. Several of the other parents also felt that they did not grieve in the same way as their partners but this was not necessarily a problem and did not prevent them being able to support each other.

Many parents feel they need to hide their true emotions. Anger is an emotion experienced by many bereaved parents at different times. One parent told how she felt let down by her mother-in-law when she did not come around or contact her on the first 6 month anniversary of her child's death but asked her the next day how she had coped. She let her know how angry and disappointed she was with her. **"It felt good to tell her how I really felt rather than just saying I was fine. She hasn't spoken to me since but I don't care"**. Another parent said she wished she wasn't **"such a push-over"**, as she rarely tells people how she really feels. She said if she did express her anger she feels like it would just explode out of her. She said her anger just boils inside her and causes her to have reflux so she takes antacids to manage this. Sometimes telling people how you feel has had good outcomes but other people cannot cope with these strong emotions and withdraw or blame the grieving person for not understanding their feelings.

For most of the evening we had been exploring how parents cope with the

strong emotions they feel after the death of their child and what it is that enables them to get up each day and to keep going. Many found routine and finding things to keep them busy essential. Finding a purpose for each day and maybe even for staying alive also helped. Setting goals and making plans related to the deceased child such as planning their birthday or keeping their resting place as they would have liked it can also help. One parent has incorporated fundraising into these activities. For some parents seeing a counsellor, and/or taking anti depressants has been helpful. One mother told us **"It (the grief) was just getting too loud and I have my other child to think about"**. The advice from one parent who had been through some very dark times was **"You just have to find one thing that you can enjoy or look forward to"**. Some of the parents who attended the group said that coming to the group helped - **"I have felt**

everything that everyone articulates" and **"When I come here I can really relate to what everyone is saying"**.

*reference to 1988 movie Sliding Doors
** Bryan Mellonie & Robert Ingpen, 'Beginnings and Endings with LIFETIMES in between' Puffin Books 1983

** Patrice Karst *The Invisible String* DeVorss & Company 2000

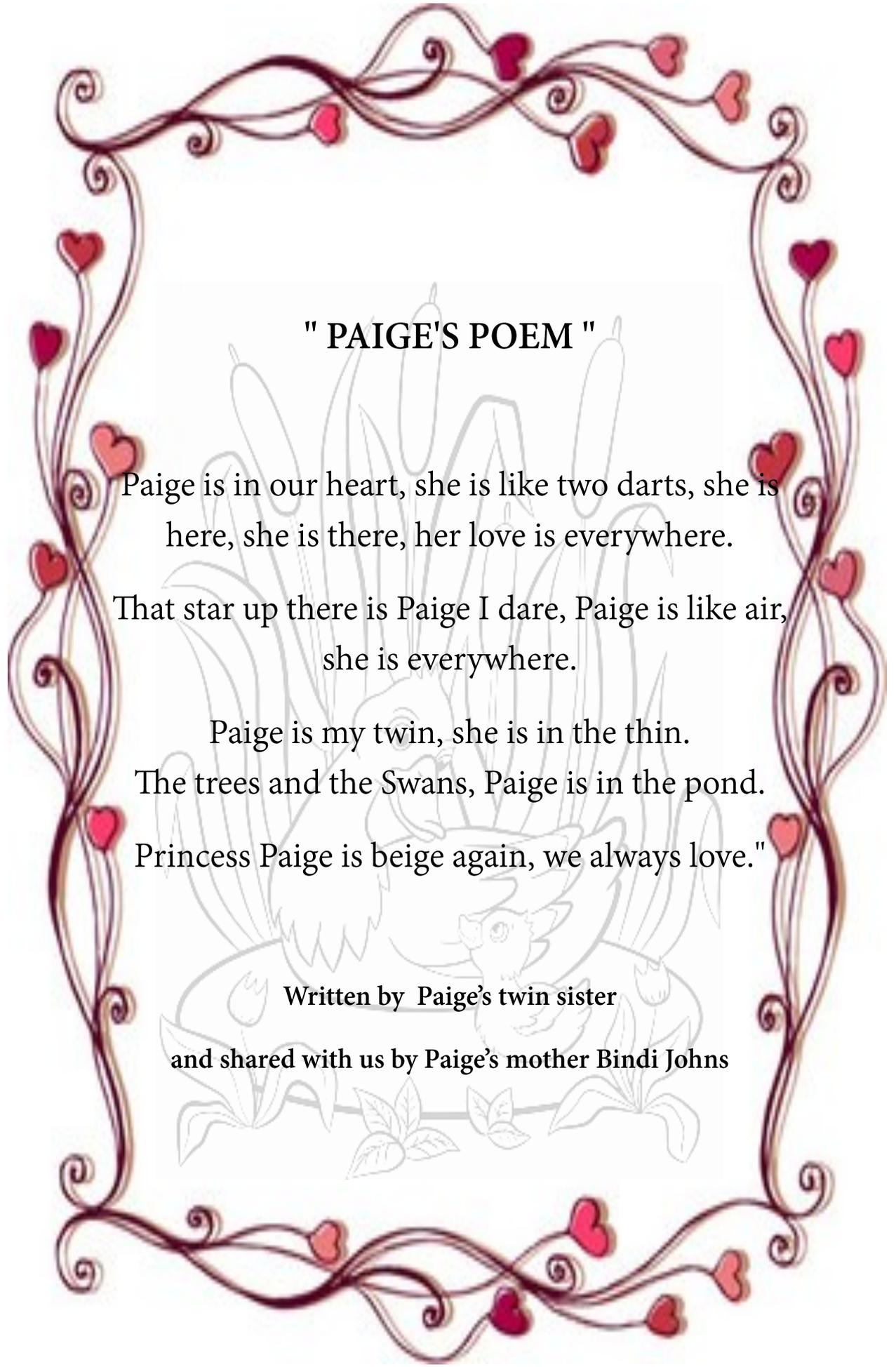
Upcoming Event

*Royal Children's Hospital
Annual Memorial Service
August 18, 2019*

*If you would like to be involved
please email:
memorial.service@rch.org.au to
register your interest.*



*We thank everyone in the group for
sharing their experiences and wisdom
and for accepting the feelings and
thoughts of others
without judgement or criticism.
We also thank you for allowing us to
share your conversations
and comments with the wider audience
who reads this newsletter.*



" PAIGE'S POEM "

Paige is in our heart, she is like two darts, she is
here, she is there, her love is everywhere.

That star up there is Paige I dare, Paige is like air,
she is everywhere.

Paige is my twin, she is in the thin.
The trees and the Swans, Paige is in the pond.
Princess Paige is beige again, we always love."

Written by Paige's twin sister
and shared with us by Paige's mother Bindi Johns

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 18th July 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:

***“Connecting with your child and looking after yourself
via music and imagery”.***

Please join us in July

*The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating, guiding the group discussion and
writing the newsletter and to Denise Browne 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.*

Social Work Department, RCH

