

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER SEPTEMBER 2017



Welcome to the September 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.

“Sharing stories of your child”

We welcomed a number of parents to the September group. Several people were new to the group and had come to tell and hear stories of their child and of the children of others. This night we wanted to give parents the opportunity to tell stories and anecdotes about their child to an audience who would listen without giving advice, without judgement and with an understanding that is difficult to find in the general community. As one parent said **“Other people will listen to stories, they know about her and that she has passed away, but nobody really knows how I feel”**. This newsletter is a little different to the usual newsletters as it is mostly a collection of stories about

ordinary, much loved, cheeky, courageous, unique children whose lives have ended far too early and whose absence has left a huge hole in the lives of their parents and families.

People in the group had different experiences of talking about their child with family and friends. Some wanted to, but felt they did not have the opportunity as reflected in this comment – **“There are days you just want to talk about your child, but to who?”** Some other parents found it difficult to talk about their child outside very immediate family because it was still too raw and it was too distressing – **“I finding telling stories about him really hard because I just**

start crying". A number of parents said they liked reading the newsletter as the stories and views in there resonated with their own stories - **"I appreciate everyone's contribution to the newsletter. Knowing there are people that understand"**, and a similar comment - **"I really appreciate the newsletters, but my partner doesn't like to read them. But I understand as it is different for everyone"**.

Everyone in the group was offered the opportunity to share a story about their child and we heard about some amazing children and some very moving stories and situations.

A number of parents expressed the thought that telling a story about your child is a precious gift you are giving to the listener. It is very painful when the person you share the story with does not understand the value of this story. As one parent put it - **"I am just not ready yet (to share stories), he is too precious. I am worried that they won't appreciate it"**.

A parent attending the group for the first time had brought along a beautiful photographic portrait of her daughter. She explained that her daughter had cancer and that this picture was taken when she



completed treatment and was in remission the first time. She said **"We had finished treatment, we had to celebrate"**. The picture showed a beautiful child, full of life and smiles. She also shared with us a painting her daughter had done in hospital several years later, after she had experienced multiple relapses. She had a significant infection at the time which required difficult, specialised treatment. In the painting she has depicted the things that were significant in her life - the hospital, her family, her school and some special people from the hospital. One of the hospital staff whom she considered the most important was the cleaner. She

told her mother that this person was particularly important because she cleaned her room every day and made sure there were no germs to give her an infection. Her mother told us - **"Everyone is the same in her eyes"**. As she told the story she said **"She was my daughter and I lost my daughter, but I lost so much"**. Every child is so much more than only a child to a parent - for this mother her daughter was a friend and companion and many other things that go into the relationship between a mother and her daughter, and all this is lost also. She told us that when she is angry or frustrated she can hear her

daughter's voice - **"I hear her voice in my head saying 'Mum, soften your heart'"**. Everyone in the group was moved by the story of this amazing young girl.

Another parent told us that she finds it difficult to tell stories about her son, as she gets too upset - **"We tell stories with each other, but we don't with others, it is just too hard"**.

She said "I always say I have 3 children ... but I find telling stories about him really hard because I just start crying".

Instead of telling a story she brought us a framed photograph of

each of her three children. She told us that her son never wasted a second, it was as if he knew he only had a short time. In the photograph he is sitting near a swimming pool. His mother said - **"He was just being a little dude"**. He was a beautiful little boy.

We also heard about a little boy who lived until he was almost 11 months old. He spent most of his life in hospital with just a few precious months at home. He had multiple heart surgeries and difficult procedures but we heard what a smiley baby he was in spite of everything he had been through.

His mother said - **"I feel like I am lying when I tell stories to people about how smiley he was, but he really really was... he was just so happy"**. She told us that a nurse had told her that babies who have been through what he had been through are not usually so happy and that he was happy because he knew how loved he was. We also heard how he had trouble



feeding as he grew and his heart was struggling more. He was delighted when solids were introduced and custard was included - **"He loved custard... he was the custard**

king".

Another child we heard about in the group was just three. He had some delays with his speech but he was still very good at telling stories and always managed to get his message across using gesture, expressions and the words he had. His mother described a cheeky little boy and told us about attending a tulip festival - **"I remember how he just walked into the gardens and picked this beautiful big pink and white tulip"**. It is tulip time again and this time brings back memories of this beautiful child. She told us he also loved to blow

out candles and said: **"I remember from last month people were talking about signs and I thought I haven't had that, I don't dream about him. It's only been two months, but last week all the candles just blew out. Maybe that was a sign from him"**.

Other parents also commented on signs or dreams about their children. One parent said she has only ever had one dream of her child – **"I've only had one dream of him in 8 years and in that dream he gave me a blue blanket. That was 2 days before I found out I was pregnant with his brother. I often think it's not fair, I would love to dream of him more often"**.

A mother whose baby boy was born just before Christmas and lived only 6 weeks told us a beautiful story about her 'Christmas baby'. She told us that she has always loved Christmas and although her baby's due date was just after Christmas she kept telling everyone he would come before Christmas so he could be there to celebrate Christmas. **"He was born on 23th Dec and I rang my mum to tell her he had arrived. I often say to people that he's our Christmas baby"**. Unfortunately he was diagnosed with a cardiac condition and transferred to the Royal Children's to spend his first and only Christmas in hospital. He was here for Christmas and had a photo with Santa. **"He has a photo with Santa that sits on the sideboard with his siblings' photos with Santa. It is so precious"**.

We were told how difficult it has been to enjoy Christmas again when it is so closely associated with the pain of those few weeks – **"It is only in the last few years that I've been able to enjoy Christmas again"**.

We heard from a father whose daughter was a young teenager when she passed away. She was able to spend her final days at VSK with family present. This was particularly appreciated as her parents were separated and re-partnered and both families were able to be with her in her final days, also at Christmas time. We heard how she shared Christmas Day with her family at VSK and that was really the last day she was conscious and lucid. When beginning to share her story, her father told us – **"There's really nothing I can say about how hard it was for me as her father... She was absolutely crazy about horses and it was really difficult for her that she couldn't get on one... She was mad for the Canadian horse show "Heartland" and we have bought season 10 and we are going to watch it for her birthday in November"**. Her dad talked very movingly about how much his daughter's illness and death had impacted on him. He had given up work to care for her as she had a protracted period of significant illness and gradual decline before she passed away. He told us **"I think I have been pretty much jaded since last December and it**

is only with this Spring that I am starting to take interest in life... I think the hardest thing for me as a father, my trauma, was the day I held her hand and told her that it was okay to go, and on that day I meant it and it was the right thing, but every day after that it has not been okay".

Her 'bonus mum' also attended the group and shared with us her experiences of grief, being the bonus mum in a mixed family. She told us the term 'bonus mum' was what her stepdaughter called her. ***"I find it really hard to know where my grief fits. It was a relief to go to VSK and to be a family and not have to be the ones managing the pain. It was great for all the kids to be together and to have that support... I have moments of crying in public. I remember being at Bunnings and I saw the pink pig for VSK*. I opened my purse to make a donation and I was a blubbering mess... I've been so blessed to have had her in my life and I made a promise to her that I would continue to be generous".*** This very honest story reminded us of the difficulty 'bonus' parents have in knowing how to show their grief and knowing where they fit in the picture when there are biological parents also grieving. The grief of the bonus family can be every bit as intense and overwhelming as the

biological family but can also feel less legitimate and thus is much more complicated. We were very grateful for this bonus mother for sharing her story so honestly.

When a child has lived a very short time it can be difficult to have stories to tell. However, even an infant with us for a short time in hospital surrounded by machines and medical equipment can still have special personality traits shining through. The parents of one such infant struggled to tell us a lot about their child but did give us a glimpse of their tiny baby's life – ***"We don't have many stories because she was so very sick... but she was surrounded by love... We managed to get a photo of her smiling... She fought really hard and we are so proud of her for that. I don't feel like we had enough time".***

These parents told us a story about the significance of the time, 4.30pm with several significant events happening at that time – ***"4.30 was quite a relevant time and I always light a candle at 4.30. It is all about the circle of life"***

Some people in the group commented how having children really changes you in some fundamental way, ***"You become proud people. He teaches you about strength"***

There was some discussion also about the expectation of other people. A mother told us that she felt after the 12 month anniversary had passed it felt like people just

'washed their hands' of her and her grief. She said **"Sometimes I wish other people would just listen and let me tell stories about my child"**.

Telling stories, being listened to and the preciousness of these stories being appreciated can be a significant way of honouring your child and acknowledging their unique place in your life and the life of your family. It can help define a new normal in your life. As one parent said: **"There is a new normal emerging for me, around this is what the loss for me looks and feels like"**.

The final story we heard in the group was also very moving. It was about a child who had lived his short life in the hospital, so many members of the extended family never had a chance to meet him in person. The mother's great aunt always makes a quilt for the grand children and nieces and nephews. This beautiful aunt presented her great niece with an exquisite hand made book with special Pandora charms on the front and on each double page a photo and a poem. The book can open out into a star. This precious and unique album was crafted with much careful thought and extraordinary love for both the child and his mother. The mother commented: **"For me at the time, I was so worried that people would forget him because he was here for such a short time, not many had the**

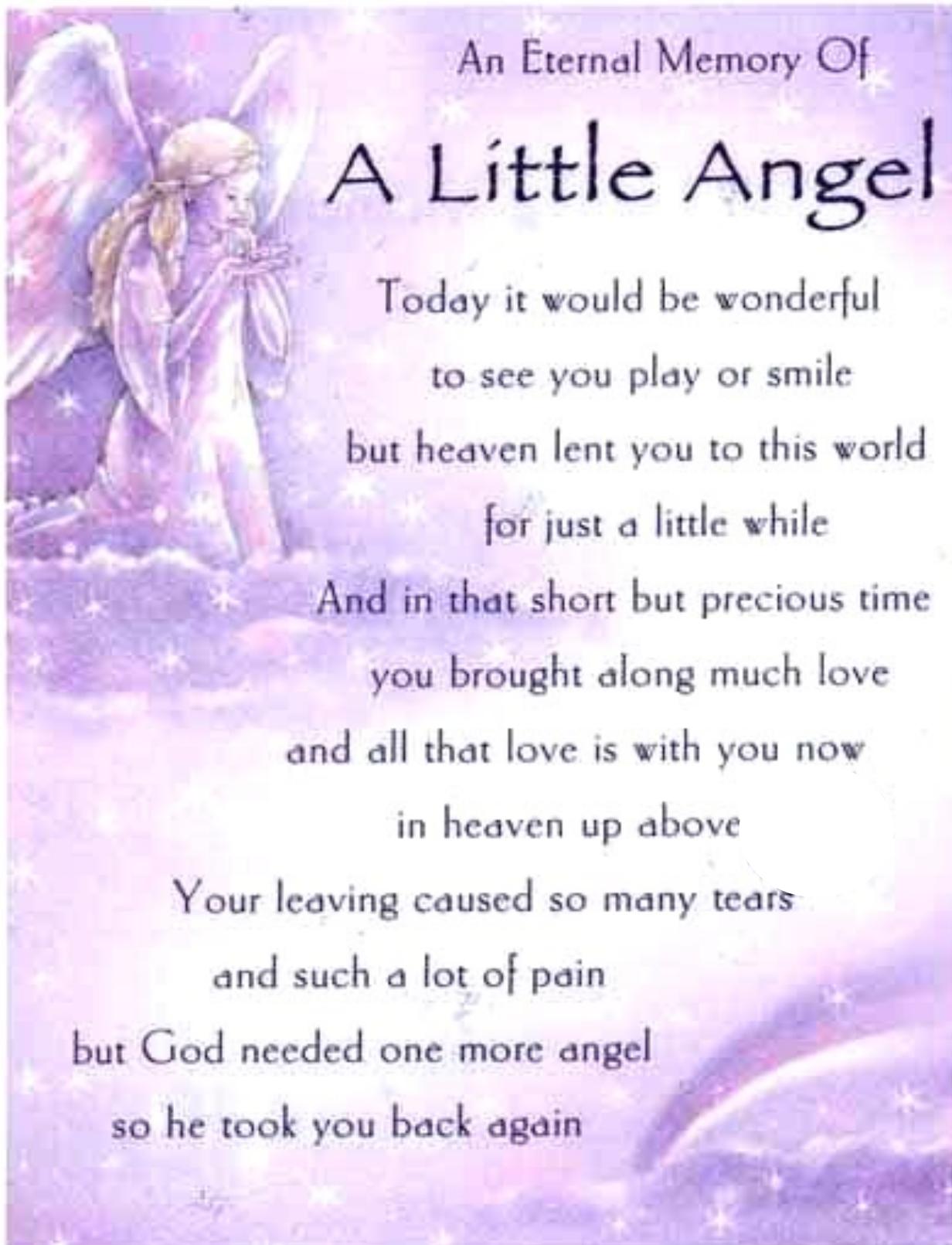
chance to meet him. It means so much to me that he wasn't going to be forgotten. That is my biggest fear". This need to remember and the fear of forgetting resonated with others in the group this night.

Stories are important in our lives. They are how we pass on the family culture and share the things that are important to us. Stories can be hard to tell, they can be healing, they can bring happiness and pain. They honour those we are telling stories about and they help others to get to know the one we love better. Stories are also precious and are a gift to the listener. Sometimes the stories are still too painful to share and the storyteller too fragile to risk the telling. Tonight stories could be told to an audience who understood that it is a privilege to be able to hear and share these stories and who understood the pain behind every story of a child who will not grow old and create more life stories. Thank you to all who attended and shared their stories. I hope I have reproduced them faithfully in this newsletter and that the readers have been able to get a sense of your unique stories.

*Very Special Kids have a large pink pig which travels around on the back of a truck to promote the organisation and raise funds.



Straight from the Heart



Source: <https://www.pinterest.co.uk/explore/christmas-in-heaven-poem/>

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 19th October
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:

***“What can we learn from differing cultural expressions
of grief, death and mourning”***

Please join us in October

*The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter
and to Wade Wright for scribing parents' statements.
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Social Work Department, RCH

