

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER JUNE 2017



The Royal
Children's
Hospital
Melbourne

Welcome to the June 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.

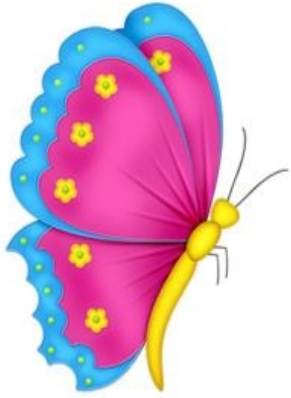
“Connecting with your child - does it have to be in pain?”

In our June family bereavement group, parents shared their stories and experiences as the discussion wove its way through the evening. The question about the possibility of remembering your child without feeling pain was explored with different perspectives and experiences shared. As usual conversation also turned to other topics at different times through the evening. I hope this newsletter faithfully represents the views and experiences of the parents present.

As always every parent was invited to introduce themselves and their child and to share a little of their story if they felt comfortable to do this. We heard of children who had lived for short and longer times and who had died from different causes and in different circumstances. We also heard about how parents are living

with their grief at this time. For one family the first anniversary of their child's death was the week of the group, and another family is approaching this time. Others have lived through many anniversaries and other significant dates.

One parent whose child died some years ago said she can now laugh and smile when she thinks of her child - **“There are more often smiles when I remember than pain now”**. This parent spoke of the other ways she can honour and remember her child without feeling sad. She feels she is with her all the time and that she is guiding her in the new paths her life is taking. **“I feel we are going to work together. I talk aloud to her in the car. I feel a different connection to her now since doing this work”**. This parent is now involved in educating professionals in how to support grieving parents - **“I**



feel like she is leading me down a path... I use my experience and share our story".

Another parent who has been bereaved for several years said she comes to the group to have time to connect with her child. Her life is busy with another child now and it is harder to have time to just remember and connect to her first child. She said: ***"I now remember him before the last 6-8 weeks of his life when he was sick and in hospital. I remember a different part of his life"***.

It seemed parents who were more recently bereaved found it more difficult to remember their child without the feeling of immense pain. One parent who has not yet experienced the first anniversary of her child's death said ***"I smile and laugh at videos which are hilarious, but I feel terrible after a giggle. There is a constant underlying sadness. I am always constantly reminded that he is not here, 24/7. A giggle leads to the thought that it was the last time or that it will never happen again"***.

Another parent, also speaking of laughing at memories said that this does not always make him feel sad, but sometimes does. Another parent said ***"All I feel is pain... Life used to be hopeful, cheery and happy... Now I am bowled over by grief and loss"***. Finding hope and happiness in life after a child has died is challenging for all parents. Some parents express a feeling

of guilt if they do start to feel hopeful or happy again. They feel the pain connects them to their child and to lose the pain is to lose the relationship to the child. Parents with more experience were able to say that this feeling lessens over time.

The impact of time was a theme that came up in the discussion, particularly with first anniversaries approaching or just occurring. One parent said that she felt the second year was in many ways harder than the first. ***"The first year you are in a fog and still in disbelief. The second year it feels it is for real, they were not part of this year... It suddenly hits you, it is real, they will not be part of the future"***. For many, this feeling of this being permanent seems to sink in more during the second year. Parents identified with the feeling that, no matter how long it has been there is still a feeling that one day the door will open and they will walk in.

People in the group shared experiences of the reactions of other people especially to significant dates. While other people may remember anniversaries and birthdays there are other days that have significance to the parents or sometimes even to one parent only. These dates are rarely recognised by others. It may be the day the child went into hospital – one parent told us about the last 10 days of her child's life: ***"We have 10 days of mourning – there was the event and then the countdown to his death... He went to sleep and we feel that is the day we lost him – he didn't wake up again"***. For these parents the day he left in the ambulance is as significant in

terms of anniversaries as the day he actually died.

Another parent talked about the significance of the day the child had **"been gone longer than he was on earth. I count the minutes and hours, trying to work out exactly when he died"**. For these parents this time is coming and will be less than a year since their child died. Another parent commented that for parents whose child died very young, this time comes quickly. She had more years with her child, so more years before this significant day when her child had been gone longer than alive.

Some people seem to think that there is a time when you should be 'over it'. Some seem to think that 12 months is long enough to grieve but others believe that even this is too long. This can be particularly disappointing or shocking when the person stating this is a health professional. Some parents told us their GP had said **"you still seem to be holding on to your grief"** when they had just had the first anniversary of their child's death. The GP had told the father that he should be over his grief at 6 months!! These parents felt that the GPs in the practice should all be aware of their situation and that it is very difficult when you refer to the child and the GP does not know who you are talking about. They suggested that an alert on the system would be helpful. This GP also appeared to be very insensitive to the very normal increase in anxiety bereaved parents feel when one of the other children gets sick,

particularly if the symptoms are similar to the child who died. This GP made the parents feel that she was only ordering further investigations because they were insistent. She also did not ward them of the risks associated with the tests.

Another parent contrasted the response of the vet to the death of their dog to the response of others to the death of their child. The vet sent a pack of materials and information and a poem for the dog and also one for their deceased child. In contrast, an organisation for families of children with the same condition as her child sent a birthday card on the day of her child's first birthday saying 'Happy Birthday Big Boy'. Her child had died just over a month before his first birthday.

People in the group had different experiences of counsellors following their child's death. One parent said the counsellor seemed 'super enthusiastic' and she felt like a case study. The attitude was - 'let's get in there and deal with your grief'. Another parent said: **"The counsellor said that 'there is nothing I feel I can help you with, you seem to be on the right path'. What is the right path?"** It seems a good counsellor does not have to say much but can listen - as one parent said **"It is helpful to debrief"**. Even funeral directors can be insensitive to the needs of a grieving person. We heard a story of a funeral director greeting the grieving family with an enthusiastic "So, tell me



what happened”.

Parents reflected that their grief makes others feel uncomfortable. Other people either try to avoid them or tell them they should be behaving in a way they feel more comfortable. One parent who goes to the cemetery every day said that a friend wanted to visit her and wanted her to stay home so he could visit her at home. She said **“Why can’t he support me at the cemetery? I feel more connected to my child there. Would he (the friend) feel more comfortable if I was doing exactly what I am doing but in my house?”** For this parent being at home is unbearable with the silence of an empty house – **“It was so quiet, I could even hear the fridge humming”**.

There were mixed feelings in the group about the motivation of other people and how to think about these hurtful attitudes. Some saw the actions of others which appeared insensitive as genuine attempts to help while others saw them as a need to protect themselves. Some in the group said they felt much more hurt if it was a family member or very close friend who didn’t ‘get it’ than when it was someone not in the family.



Being able to talk about their child was very important to many parents and others who allowed or even invited them to talk about the child were much appreciated. For some parents, however having quiet time to reflect and think about their child was more helpful. A father told us that he has little contact with his fellow employees at his work place and when he does they would never talk about his child. He said: **“This gives me time to think about him more. I have photos up and one looks like he is winking. I wink back at him”**. This father talks to his partner about their child and usually phones her to talk during the day, but he does not feel the need to talk to anyone else.

Another couple said that their colleagues are very supportive but also spoke of the dilemma when clients ask why they were away or ask about their child. **“Clients ask about why I was on leave. I don’t want to lie, but it is hard to say why. It is hard to be professional when I am falling apart. I try to compartmentalise”**. For some parents work represents a productive, purposeful and meaningful part of life. For some work provides a temporary escape from the intensity of their grief.

It can be very difficult for grieving parents to feel comfortable in social situations. As one parent said: **“Social situations are really hard. Conversations are really hard. I’m not like I used to be. I really struggle”**. For many, small talk seems really trivial. Questions about your children

and about how many children you have often come up at social events. A parent shared a story with us about her response to a question by a stranger about how many children she had: **"For the first time in the 9 1/2 years since my child died I answered without hesitation – I have two boys – one is 2 1/2 and one would be turning 11. He is no longer with us, he is in heaven. Later in the conversation she asked what school our son goes to. I had to say it again, she didn't even listen the first time"**. Such insensitivity is extremely upsetting and, as this parent said it makes you think, why even bother to try to be social. She also told us about an analogy a counsellor had suggested. She had said that sharing the story about your child is like having an expensive box of chocolates. You don't share those chocolates with just anyone, only with special people. As the parent said of this person– **"I felt like saying, you don't deserve my box of chocolates"**. Sharing your story is very personal and very generous. Not everyone can appreciate the gift you give when you do this.

The conversation continued with discussion of videos and different parents' feeling about watching them. **"I watch videos now and smile and laugh. There is still sadness though as I want to give her a hug and a kiss"**. Some in the group said that they have watched the videos since day one while their partner still can't watch them. One parent said she



still can't watch the videos. She said **"I can't watch them because I can see how much he struggled. You don't see it as much when you are living it. I watched one of when he was in the old hospital. I do have some happy ones"**.

The topic of the impact on other children and of having another child was also raised. A couple told us that when they had a car accident and one of them was admitted to hospital their child was very distressed as he thought that people die when they go to hospital. We also heard about the pain and joy of having siblings talk about their absent sibling. Parents also discussed the struggle of trying to keep life normal for the other children. **"You can't fall apart all the time. The children need time with happy mum. We play games and go to the park, then I fall apart again"**. Some parents have reached a time when they can talk about their child without getting upset – **"He sees me talk, laugh and remember her with smiles, not always tears. It took a number of years, though"**.

Some of the parents in the group had had another child since their child died and others were wondering how they

would cope with this if they were to have another child. One parent said she felt like she was in the dark until she had another child. She said once she had this child she could remember her first child in a different way, remembering the positive things, not only the later part of his life when he was struggling more. A parent who had not had another child wondered how she could have another child and still be the mother to her first child the way she wants to be. She is afraid she will not have the time to spend connected to her other child. Other parents shared their experiences of having similar fears – fears that they would not be able to love their new child enough, that they would not be able to share their love. One parent assured her that one child will never replace the other. A parent wisely said – **"Your heart expands, you can fit more love in it"**. The fear of not knowing how to care for a healthy child was also raised. Fear of overreacting to little, normal things, fear of being hyper vigilant, fear of simply not knowing how to parent a healthy child. One parent who had not been able to have another child for 7 years after the death of her first child said **"For seven years my sole focus was just on my first child, now I have another. You have not even had one year yet"**. The experience of the group was that siblings learn to co-exist and this is so whether the sibling they have is alive or gone.

Parents in the group also talked about

the similarities and differences between their children. A parent told us **"I can see traits of her in her brother, sometimes it can take my breath away, but in a whole lot of other ways he is his own unique person. It is a gift"**. Another commented – **"They look alike but they are so different"** She also told us that she feels like her first child has never completely gone, that he is in the house everywhere. Another parent said she feels like her child is still here, that he is on the ward or in surgery. This feeling is very common among grieving parents. A parent whose child died over 5 years ago said **"I still think the door might open and she will walk in. If she did I would accept it, no questions asked"**.

The discussion this evening had gone where the group needed it to go with parents expressing their concerns about remembering their child and continuing a strong connection to them. Different parents manage this in different ways and this may change over time. Life is complicated with home life and other children, work and social situations to navigate. Sharing your story with another is a precious gift and not everyone can appreciate it. Tonight the people in the group shared their experiences, their wisdom and their fears and frustrations generously and honestly. For those who were present I hope I have shared your stories faithfully and for those who are reading this newsletter I hope these stories resonate in some way with your own. Please feel free to send us your stories, prose or poem and we will be happy to include them in the newsletter.

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Straight from the Heart



A Child Never Forgotten

*Our heart was broken
without a warning, no words spoken
you were taken away
someone said you could not stay*

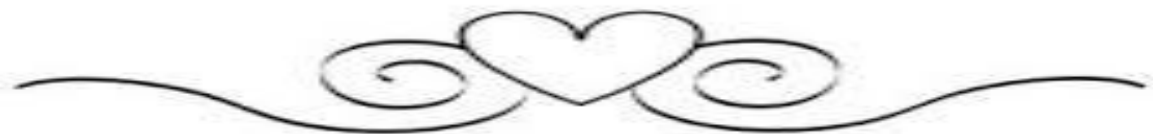
*empty and lonely is what we are
we lost a precious shining star
our family torn apart
your world began with a promising start*

*life is unfair
this difficult cross we must bear
strength and courage we will find
our special child always in our mind*

*a place in heaven is where you sit
looking at that star you lit
in our thoughts forever you will be
never knowing why someone set you free*

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Source: <https://www.familyfriendpoems.com/poem/a-child-never-forgotten>



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 20th July
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:

“The stories we tell and the meanings we make of them”

Please join us in July

*The newsletter is always a team effort.
Thank you to Helen Stewart for guiding the group discussion and for facilitating
and to Maria Poppelwell for scribing parents' statements.
Also to the RCH Volunteers & to Jenny Jelic for ensuring
the newsletter is formatted and distributed to interested people.*

Social Work Department, RCH

