

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER MAY 2017



Welcome to the May 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.

“When grief is all - encompassing is it possible to think of others?”

This month's group considered the difficult question of how, when one is overcome with one's own grief, one can possibly think about other people's experience or distress. Participants demonstrated the complexity of the topic, sharing the overwhelming nature of their loss together. They conveyed how hard it is at times to relate to the experience of others who have not been through this devastating loss. This is especially so if these others appear to be insensitive to their grief whilst still expecting them to be empathic



around seemingly small worries and concerns. This is incredibly hard to listen to and respond to when you have lost a child.

The session began with introductions and participants speaking about themselves and their child. One couple talked about their son's battle with illness and how in the end he just became "too tired". Some talked about the difficulty of approaching or recent anniversaries. One mother talked about her recent struggle with the fifth anniversary of her daughter's death, and how for some reason it

had hit her particularly painfully. One father whose child died last year spoke about how he and his wife are confronting every new milestone one by one, **"even the seasons changing. There's a tree out the back and all the leaves are falling off. It's just a constant reminder"**.

With Mothers' Day having recently passed, many participants spoke about the challenges of this, how they mourned on this day, how they got through it and their struggles to find connection and support with others on this day. One mother related how her second child **"got me through mother's day"**. Another agreed: **"My daughter is six and she gets me up every day"**. Yet another, whilst remembering beautiful images of her child who died, who was **"full of beans, so smiley all the time, loved custard and watermelon"**, stated **"this mother's day was a mess"**.



One couple spoke about how they have not yet been able to find out **"what was wrong"** that caused their child's death late last year. This mother found mother's day particularly hard as she had also just had a miscarriage.

Many parents expressed that how much one can relate to others often depends on how much they are able to understand and support them as a bereaved parent. One mother described how she had tried to share her feelings with her mother in law who had been very close to her granddaughter. She was remembering her only mother's day with her daughter who was in hospital in a wheelchair, attached to tubes, and how she gave her mother a rose. On Mothers' Day this year this mother went to her son's school and **"cried the whole time"**. When she described these memories and experiences to her mother in law, she replied that **"you have to block those feelings out"**. Such statements are very unhelpful as they can make parents feel hurt and/or guilty for thinking of their child. It is also very hard to maintain supportive relationships with those who speak in judgemental ways about your grief. Participants spoke about their frequent difficulty connecting with those who suggest they should repress or get over feelings

and thoughts related to grief. This can be so even with family members or significant others.

Acute grief can also change one's sense of relationships more broadly, as one tries to juggle on the one hand the need for relationship with one's departed child, and on the other, relationships with the living. Even the comfort of other children can be strange and painful: **"It's like a parallel world. For every experience there's like a parallel door with everything happening with the other child"**. This notion of a "parallel world" resonated with many parents. One described this parallel world as comforting, nine years down the track: **"It's my way of continuing that relationship. Watching my two and a half year old chase his dad... I sat there on the curb and thought 'What did we miss out on? What would [other child] be like?' It's exhausting but comforting"**. Another stated: **"Being our first, all the things we missed out on were hypothetical. I just had a thought in my head about what they would be like. With my other son now I know what I missed out on. The first year I got a mother's day card handwritten by him at school, I thought I'm never going to see**



what (other child's) handwriting looks like. The kids have their birthdays and family things and for me there's a little shadow that he's not there".

Two mothers described the strange perceptual experience of worrying about their dead child as if they were still alive. Even though logically they know their child is no longer here, there are moments of intense worry as if the child was in present danger. One mother, whose child died at home in her arms, sometimes worries **"What if it had happened at school, or in hospital and I'd left the ward and told the nurses that I had gone to get some chips and they called a MET and by the time I got back she'd gone and I wasn't there?"** Another mother wakes up worrying if her child is alright in his cot: **"I'm still worried that he will die. I know he's passed away but I'm constantly nervous. I don't**

watch the news anymore but sometimes on Facebook you are scrolling and you see something and there's been some break-ins recently and I wake up at 4 o'clock on the dot and I think he's in his cot and that someone will break in and hurt him. I'm nervous to have another child if I already feel like this about him". When these concerns, experiences and perceptions are so profound, it is at times very hard to connect with the common preoccupations of the world of the living.

One mother talked about how it's harder to be present to the living sibling - given that at times they can be a reminder of all the potential experiences you have missed out on with your child who has died. This can be hard on the surviving sibling. **"He knows that with everything we do, (our daughter) is in the back of our mind. He's missing out on the childhood he deserves. He knows that Mummy and Daddy are sad because she's not here. You think about what you've missed out on, because your other child is there".** At the same time it can also heighten worries about the surviving sibling. **"We had soccer tonight and he took a ball to the face and I was fully in the moment then but then panic set in."**

Parents at times even think twice about coming to the Bereavement group due to their worry that something might happen: **"Should I go to the group in case something happens to him? You go into panic mode. There's an underlying fear under everything they do".**

Usual reassurances about statistics and probability of bad things happening no longer work for many bereaved parents. One group participant described **"You always think "it can't happen to me" but the worst has happened so you know it can happen to you. My brother forgot to pick her up from school and when I got the call I started to panic because I imagined her on the side of the road on her own which wasn't the case because she's in prep and her teacher was with her the whole time. It took me twenty-four hours to calm myself down from that. It can happen to you".** Another stated **"My doctor told me once 'you've been struck by lightning' - I use this to explain why I'm so anxious all the time".** Yet another parent described living in a **"heightened state. It's not a healthy position to live in. It's not just about the other children".**

One parent expressed that the experience of grief and of others' response to that grief, makes it **"impossible to connect with other people"**. Another agreed, stating it makes her angry **"when people make a big deal about small things. But for them it's this big thing"**.



Another parent talked about how over time one can be a little more present to others and their concerns: **"As I've gotten further along and time has passed I'm more able to be in the moment with them when a small thing seems big to them. I couldn't before"**. It was pointed out that **"early on you have to be selfish with your grief just to survive. They might get offended by that but bad luck. Being able to do and say things is important. There will always be people who say 'why haven't you got over it yet?' - but it's your grief to deal with. You have to deal with it"**. Another parent agreed: **"They expect you to go fix it and then you will come back as you were before. They don't realise that everything has changed"**.

The **"onus on us (parents) to be patient and understanding"**

is exhausting at times yet bereaved parents frequently feel they are not offered the same patience from others. One mother stated how she now thinks of people as being in "two camps" - **"there's a shrinking pool of people who I can always rely on to be patient. They are there regardless, no need to interpret or compare, or add to"**.

Parents also spoke about being "scared to lose people", and worried as to whether ultimately it will only be themselves and their partner who can understand their experience. **"There isn't really anyone else"**. Some parents spoke about the loss of connection with the hospital and people working there, that happens after your child has died. **"You lose contact with people - like a medical team that you may have regular contact with. For us it was the girls down on the (hospital ward). I was in on Monday and I went to see them. I took them a cake. I said 'do you realise we've known each other ten years?' In the last month of her life I spent more time here than at home and then all of a sudden "bang", they're not there"**.

One parent who identified how difficult it was when the contact

with hospital staff ended after her son died, wondered whether there might be a better way to involve parents post death. Others talked about missing the hospital itself when being there has become the major focus of your life: **"I miss coming here. It's a stupid thing to say and think but we were here every week for a whole twelve months. It's your life"**. Many felt that the loss is felt because of all the memories of your child that are held in the hospital. For some there is a closeness with their child which they can feel strongly within the hospital, particularly if they spent a long time there or died there.

The longing to be acknowledged as a parent after your child has died, and to always acknowledge your child who has died as being forever your child, was spoken about at length in this group. Parents have different ways of dealing with the question "How many kids do you have?" One mother stated **"I used to say "I had two kids; one died", but now I don't"**. Other responses were: **"If I say 'one' then I feel like I disown her", and "I say 'one here and one in heaven'"**. One mother talked about how important it is for her to be still

"identified as a mum", the struggle to get this recognition and the ongoing wish to talk about her child, show photos and be acknowledged in these interactions as a mother: **"I want to shout to someone: 'I'm a mum'"**. In response to this another mother spoke about one of the teachers at her daughter's school confiding she had a dream about her daughter. This mother found it sustaining to hear this confirmation of someone's enduring memory of her child, **"just to hear her name and that someone was thinking of her"**. Perhaps this kind of acknowledgement and remembering by others, when articulated to a bereaved parent, can also assist the parent in maintaining connection both with their child, and with those living who are able to understand the importance of holding the child in mind and memory.

Thanks to all who attended, reflected and shared their thoughts and experiences with the group.



Straight from the Heart



Thank you to **Bernadette Houghton - Brennan's mum**
for her contribution.

There's a hole in my heart that will never heal;
It's now been three years, but still doesn't seem real
That we lost our dear boy, our darling Brennan,
Never to hug him or to see him again.

The years that have passed have been forlorn and sad,
With our minds filled with thoughts of the joy not had.
Though we laughed and we smiled and got on with life,
Behind all the smiles was a heart smote with strife.

A heart battling anger, a heart full of rage
That our son had been called at so young an age.
Before he had lived life, on the cusp of man,
His life wrenched from him, our darling Brennan.

The loss of our boy, with his laughs and his jokes,
His love and his glee and care for other folks,
Has left us bereft, has made our lives forlorn.
We so loved that boy from the day he was born.

That hole in my heart, I would rather it stayed;
I would rather it deepen than ever fade.
That hole in my heart shows the depth of our bond,
A bond that will endure my life and beyond.

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 15th June
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 - Does it have to be in pain?”

Please join us in June

*The newsletter is always a team effort.
Thank you to Robyn Clark for guiding the group discussion and for facilitating
and to Melainie McKay 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

