



FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department
Royal Children's Hospital

NEWSLETTER JUNE 2009

Welcome to the June 2009 edition of the Family Bereavement Support Programme's Newsletter. We hope that as you read the reflections of the parents who attended the Group that you will share a connection with their thoughts and feelings, gain an increased understanding of what you are experiencing, and find hope for the future.

'Time, Memories and the Legacy Our Children Leave Us'

The parents who came along to the June Meeting of the Parent Bereavement Group were warmly welcomed, and it was acknowledged (for one couple who were attending for the first time) that it can be difficult to walk through the door to the Group for the first time. That being said, it was important to note that they had come to a place where they were in the company of others who understand, better than anyone, what it is like to have a child die. It was explained that they were in a safe place where they could share what they wanted to share, listen to others, ask questions and, most importantly, talk about and express the love they have for their child who has died.

It was explained that hand-written notes would be taken during the evening, and that these notes (which contain no identifying information) form the basis of this Newsletter. It was noted that the Newsletter is known to be an important means of sharing experiences with other bereaved parents and family members who are unable to attend the Group.

The June Group was a little different to most other Parent Bereavement Groups held at the Royal Children's Hospital, as this month we did not have a guest presenter. Instead, the Group was more like a Support Group, with those present being provided with an extended period of time to speak about their children, and more opportunities to share their own experiences of what has happened since their child died. Although, due to unforeseen circumstances, we could not

address the advertised theme for this session, the themes of 'the passage of time', 'creating meaning and memories', and the 'legacy' the children have left with their families became the dominant themes of the evening.

The children whose parents attended this Group were aged between 5 months and 10 years of age when they died and they died between ten weeks and twenty-six years ago. The children died from a number of different causes including a congenital condition, complications surrounding leukemia, a heart condition, SIDS and a home accident. The majority of the children had been the only child. Three bereaved fathers and five bereaved mothers were present.

As noted above, the June Group offered those attending more time than usual to speak about their children who had died. Each parent spoke lovingly and movingly about their child, his or her life and how that life had touched them as parents and others who knew the child. Time was also spent speaking about the days and weeks prior to the child's death, what happened, and what has happened since. Photos were passed around and those present spoke with pride about the special qualities of each child. Tears were shed with some smiles and laughter which were shared throughout the evening.

Following are some of the thoughts and feelings spoken of during the Group.

The need for hope:

Recently bereaved parents often speak about the need to hear from other bereaved parents who are further 'down the track'. In the early days following a child's death, it is important for most people to be given 'hope' that they too will survive the death of their child. And, it is the sharing of other parents who have experienced a similar situation, although some time ago, which provides this 'hope'. Given that a couple who were attending this Group only ten weeks after their little daughter died suddenly and unexpectedly, other group members were encouraged to reflect back to what they were thinking and feeling two to three months after their child died, and how things have changed for them since then.

The passage of time:

One parent, when reflecting on what it was



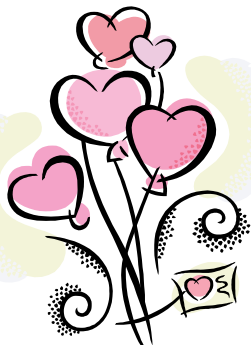
like for her in the early days following her child's death, said: **"I think wanting to join your child is common in the early months. In fact, nowadays I'm not afraid of dying. It means I'll meet up with (my son). For a while after he died, all I could see were visions of what was bad at the end of (my son's) life. Now, sixteen months later, I am not so consumed by the horrible stuff. I am remembering the good stuff. It really does get easier."**

Another mother explained: **"At the two month mark (since her daughter's death), we were getting ready for her birthday and Christmas. I prepared myself for those two events, but I totally forgot about the impact of New Years Eve. I was suddenly confronted with facing the fact that I was about to begin a whole new year without her. That was hard. It's now nineteen months since she died and I have to say it is getting easier Soon she will have been dead longer than she was alive ... that's hard to deal with. Knowing that I'm never going to see that little face again ... not going to see her reach those milestones (that other children reach). That's hard."**

One mother said: **"It got worse about the six month mark. I felt lost. I isolated myself ... I didn't want to be around other people ... didn't want to go to the shops. At the six month mark I felt as if I was on 'auto pilot'".**

A father explained: **"It's now four years since (my daughter) died. In the early days it was awful. I missed her so much. I still miss her. I'll always miss her. But now I know I will have some peace. Back then it was so hard to talk about her without crying. Now though, I can talk about the funny things she did. Back in the first year, talking about her was so painful ... the stories about her were painful ... but now, I love talking about her and the funny things she did and said ... because that is who she was."**

He added: **"In the early days, I had no control over my emotions ... things just exploded ... I blurted things out ... I burst out crying ... It would come as a surprise ... this big**



black cloud of intense emotion would descend ... I was literally at its mercy. Now, (four years later) I have some control over when these emotional storms descend. I can say to myself: 'Now is not the time'. I can promise myself that I will allow myself to cry at another time, say on Saturday. I have some control over my emotions now."

Returning to work and dealing with remarks from colleagues:

One mother said: **"Going back to work was hard. I found full-time work was out of the question. It was too hard. Too exhausting. I decided to just work three days a week ... I could manage that."**

Because the death of a child is such a difficult subject, many people may not know how to respond to you. While most people will want to be supportive of you, some may unintentionally say and do the wrong things. This mother went on to say that at times she feels excluded from conversations at work when colleagues speak about their children. She said that at work, **"when (she) mentions (her son's) name, conversation stops.** She went on: **"It's as if you don't have the right to be in the conversation about colleagues' children."**

Creating and protecting meaningful memories:

Over time, most parents find that doing or creating something in memory of their child is a helpful way of continuing the loving bond they have with their child. A mother explained: **"We did a party for (our son). It was very therapeutic. We had a banana cake and other kid's stuff such as party pies and so on. We had all the kids around a table, just as would happen at a normal kids' birthday party. We had all of (our son's) favourite food, including a huge bowl of spaghetti bolognese. We took some photos of it so that we could remember. We have created a number of Memory Books for (our son). They are just exercise books. I have given one to each of my sisters and have asked them to write down anything they remember about (our son). It's nice to write ... any thoughts at all ... I'm worried I'll forget, and this way, the things that other people remember about him and write down will help me remember too."**

She went on: **"I wanted to make a special poster of our son but I can't bring myself to cut any of the photos we have of him. So, I gave a copy of all of the photos to a**

friend of ours who is a photographer. He came back to us a few weeks ago with this huge poster ... it's almost the size of our lounge room wall! It's the storybook of (our son's) life. It was framed and given to me on my 30th birthday. Wonderful!"



Another parent explained that she **"collected treasured things and put them in a box... framed photos, and a tree branch upon which people at the funeral hung cut out cardboard hearts. I still have the tree branch, and soon I will break it and place it in a frame. There are also photos and handprints which were taken when (my daughter) was in Intensive Care."** This parent also spoke about the 'slide show' which was developed for her little girl's funeral. It has wonderfully animated images of her little daughter **"blowing kisses and saying 'Uv you Mumma'."**

Following on from this the parent whose son died twenty-six years ago laughingly told the Group that **"times have changed. We didn't have digital cameras back then, just negatives from which to make copies of photos. I have placed all of the negatives and photos of (our son) in a safety deposit box at the bank."** This is an example of how precious such items are.

The value of journaling:

The Group acknowledged the value of talking and in some cases writing about their experiences. The parent whose little boy died twenty-six years ago, told the Group how, about three or four years ago, she brought together all of the photos she had of her son's short life and wrote a two page piece about the day he died and her pregnancy prior to his birth. She said she was surprised and amazed as she looked at the photos that she could remember so much of the day he died and the aftermath. This helped her to write about her experiences. In speaking about the value of writing and journaling, she remarked: **"I've written so many letters to him ... I think we should just do it in our own way."**

Attending Memorial Services:

A number of the parents present spoke about the value of attending Memorial Services such as those organized by SIDS and Kids, Very Special Kids and the Royal Children's Hospital. While at times Memorial Services can be very sad, (for

example seeing all of the photos of children at the front of the Church during the SIDS and Kids Memorial Service) it was the reading out of the children's names which had the most meaning for parents. You may consider attending the Memorial Service at the Royal Children's Hospital on Sunday 30th August 2009. Please inform the Social Work Department (ph 9345 6111) of your child's name which can then be read out during the Service.

Support from friends and family – over time:

Most family members, friends and colleagues want to be helpful although, at times, they may not know what to say or do.

A recently bereaved father said: ***"I've had great support from a small number of my friends ... some of whom I wouldn't have expected to be supportive. We are finding that some people are uncomfortable just to mention her name. They seem to think we might cry if they mention her ... they don't want us to cry. I guess 'death' is still a taboo subject, and people don't know what to say."*** He added: ***"One of the people who has been very supportive has also lost someone he loved very much."***

Another father had a similar experience. He explained: ***"Our best friends' daughter died eighteen months before our daughter died. They really knew what we were going through ... still do. And another lady sends us flowers and a card every twelve months. That has been so helpful to us."***

A mother added: ***"We've had wonderful support from my sisters. They speak of our son a lot. Probably the most support we've received is from two couples who were in the Hospital with us. We've all had dinner together many times now, and although the children's deaths no longer 'head' the conversation, we always speak about them."***

Another mother said that her sister and mother had been her best support over many years, and a friend whose child died at the age of five had provided empathic understanding over the years.

Another father explained: ***"We***



had fantastic support from many people in the early days. But, people have short memories. After a few weeks you find that there is a 'mismatch' between what you (as a bereaved parent) are thinking and feeling, and what other people are thinking and feeling. Over time, they go back to their lives, work etc. and they forget the person who died. I didn't forget though. (My daughter) was always foremost in my mind ... for every minute ... every hour ... every day. But for other people ... they stopped thinking about her and what happened to us."

A mother said: ***"People gradually get on with their lives. But my life is irreversibly changed."***

One parent explained that at a SIDS and Kids Memorial Service which she attended a few months after her little boy died, she heard a father use the following analogy: ***"After a child dies it is as if the parents go on a train trip together with other people for a while. Then, over time, and at different stops, people get off the train. These people may be family members or friends. They get off at different stops ... sometimes a couple get off at one stop ... sometimes a few get off. But they eventually all get off the train. But you ... the bereaved parent ... are on the train until the end of the line. But the journey does get easier and it's not all up hill."***

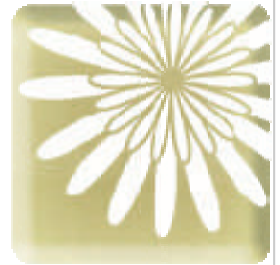
The legacy the children leave with their parents:

Parents spoke eloquently and movingly about the impact their children had had on them, and the legacy each of the children had left.

One parent spoke of her little boy guiding her throughout her adult life, and that the work she does is in memory of him.

What was very apparent is the resiliency which is often evident within people following a tragedy or trauma. As one mother said: ***"Now I can see through the fog. This whole experience has been life changing for me and for us as a couple. We appreciate things more now. And my internal dialogue is different. Now I know I can get through anything. That is my son's legacy. He's made me so much more of a better person. He's made my relationship with my partner stronger. I probably help other people much more now than I would've had this not happened. And that's all thanks to my son."*** A father added that he and his partner

"can identify each other's strengths now ... that is (our son's) legacy."



As one mother explained: ***"My little girl was so sick throughout her short life. She taught me to appreciate every single moment, because that's what she did. I had to say to (her) 'You can go now ... You don't need to stay for us'. That was such a painful thing to say and think ... She was such a huge part of my life ... she was and she still is ... she taught me to appreciate people ... to try to tell people that I love them, because we don't do that enough. She didn't have many words, but she could say 'I uv you' ... we need to tell people close to us that we love them ... that's her legacy to me."***

Another parent said: ***"You may have outlived your child. But that doesn't mean you can't live a worthwhile life. I want to live a well-lived life. I have no idea how, but I want my life to count for my child."***

Support for each other:

Once again, the bond between parents was very evident throughout the evening as they provided empathic support to each other, listened carefully and spoke thoughtfully, respectfully and compassionately to each other. All acknowledged the individual 'preciousness' of each of the children, and one explained on behalf of all present that coming to the Group ***"is a time devoted to the children, where we share our love for our child and get to know your child."***

Ongoing support:

The ongoing services of the Social Work Department of the Royal Children's Hospital and other bereavement organizations like SIDS and Kids and Very Special Kids were mentioned as useful ongoing support options prior to the sharing of biscuits, coffee and friendly conversation.

Vivienne Bateman
Social Work Department
Royal Children's Hospital

Straight from the Heart

Thanks to Vicki Manton for sending this reflection for inclusion in the Newsletter. Vicki's son Joshua died at the Royal Children's Hospital in 1993 aged five.

21 today

I wrote an article for this Newsletter a little over 12 months ago as I reflected on the fact that our son Joshua, who died when he was 5, would have been 20 years of age.

As our friends with children of a similar age started to plan 21st birthdays for this year we wondered what we would do on this day that is such a rite of passage and joyous occasion for most families.

We were firm on the idea that we wanted to mark the day and as the year progressed and I thought about it and discussed how with my husband and children I gained this picture in my mind of what we wanted the day to be. The oddest thing was trying to describe to people what it was we were planning. Not a 21st in the traditional sense, not a celebration, not a get together to be miserable company. A celebration of all the things Joshua meant to us.

We invited only our close families and four other families that were our friends and had known Joshua well. Our other friends, our "post Joshua friends" we hoped would understand. We went to a park in Healesville that my family had loved when I was growing up and one we had taken Joshua and our other children to. It was extremely child-friendly and safe for all the little people who would be present. We asked everyone to bring bikes and kites and footballs and remote control cars and we asked them to play and be silly.

And we did exactly that. It looked like it would rain right up until we left. I might add this was 4 weeks after the bushfires in the Yarra Valley and in the middle of the longest dry spell anyone could remember. However we chose a spot with a big roof in case of this eventuality. The smaller children rode around us on their bikes with training wheels dodging remote control cars that constantly threatened to trip over anyone silly enough to be walking and the larger kids including myself rode loops of the park with them; my brothers who have not been on bikes for years included. We played a version of football that actually resembled British Bulldog or rugby and surprisingly broke no bones.

We didn't do cake in the traditional sense but my very great friend brought a large chocolate cake that was a hit.

And if there were tears when several people spoke of their memories of Joshua and how much we missed him they offered an opportunity for much hugging which was nice.

I am so proud of my children for the way they supported each other and their parents and the enthusiasm with which they threw themselves into the day. This day was the culmination of 6 weeks spent at other children's 21st birthday parties. We went to these parties happy to share in the joy of our friends' children reaching maturity and moving into the adult phases of their lives. But I have to say it was very difficult at speech time to look at these strapping young men and not hate from the bottom of my soul the fact that we were not planning such an event.

The 21st was a final step in a sequence of milestones that our children go through on their way to adulthood; transitions through school, driving, girlfriends, uni and careers. Up to 21 these are things our children do together. After this the milestones weddings and children are at no fixed time. I have to say I am grateful for this because up to this point as our friends' children have passed through these milestones we have been included but always excluded because we do not have our son.

This day was everything we could have hoped for and so much more and if we have not quite been able to look at the photos they are not going anywhere and I will when the day is right.

We felt as if the 21st was a watershed in a way that I cannot describe. But I felt more peaceful at the end of the day.



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 are most welcome in the Newsletters. Share your thoughts, experiences & questions with others who are bereaved.

Please forward them to:

The Editor
Family Bereavement Support
Programme
Social Work Department
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Phone: 03 9345 6111
Or email: carly.blanche@rch.org.au

The next meeting of the
Parents' Bereavement Support Evening
Group
will be held on:

Thursday 18th June
7:30 pm – 9:30 pm
Seminar Room 2, 4th Floor
Front Entry Building
Royal Children's Hospital

At the July group we will be joined by John Downes, Social Worker with the Road Trauma Support Service who will speak on a topic of interest to the Group.

Please join us in July

The newsletter is always a team effort. Thank you to Carol Quayle for co-facilitating the Group, and to our skilled committed Admin Team- Carly Blanche, Rebecca Welsh and Sam Harris.

Vivienne Bateman
Editor