

PARENTS' BEREAVEMENT SUPPORT GROUP



Social Work Department
Royal Children's Hospital

AUGUST 2006 NEWSLETTER

Welcome to the Newsletter of the Family Bereavement Support Programme. We hope that within the words of the newsletters and the experiences of the groups you will find connections with others, encouragement and resources to help sustain you as you grieve for your child.

“From Thoughts and Words into Music and Song”.

We warmly welcomed parents who joined the August group. In welcoming the parents we acknowledged their children who had brought the parents together for this evening's group. We especially recognised the experiences of those coming to the group for the first time and spent a few moments introducing the group. Most months there is a suggested theme to explore during the evening and usually a guest presenter to help us do this. The group however is *very much a parents' group* where the direction of the discussion is guided by parents. The group aims to be a supported place where parents who are grieving for their child, feel able to share their family story. We hope that during the evening there is an opportunity *to get to know the children*. Parents are invited to be involved in the group in ways in which they feel comfortable. They are encouraged to move *in and out* of the group as they feel comfortable. The monthly group is available to parents to come to as they find is helpful.

Notes without names are taken during the group to help create this newsletter. Carol and Jane are available to talk more privately with parents either by phone or in person between groups.

Through unexpected circumstances our *advertised* guest for the evening was unable to come to the group. We were very pleased, however, to be able to welcome her colleague Ms Katie Lindenfelser. Katie is a music therapist who has worked in hospital and hospice settings in America and more recently in Australia. Currently, Katie is completing her master's study which is focusing on bereaved parents' experiences of music therapy with their children. Katie would during the evening talk more about the nature and role of music therapy in supporting parents and young people as they face issues of change, loss and grief.

Katie began by expressing her sense of privilege at being with the parents and her hope that parents would feel able to explore something of their relationship with music and the relationship between their child and music through the night. Katie also invited parents to think a little about how their relationship with and experience of music may have changed since their child's death. Katie had *brought* with her to the group, several processes to help parents to experience the possibilities of music.



Later in the evening Katie would ask group members to decide which of these they wanted to *try out*.

In the conversation that followed Katie would also acknowledge the impact of returning to the Hospital, saying “It is very meaningful. This a new time, a time to be together, it’s huge”. Katie spoke about how parents in the group had “similar yet unique experiences” and “the importance of being able to see others” who were living with grief. In response a mother said **“in the group everyone here knows what it’s like. A counsellor can be understanding but it’s not the same. Here people don’t have to say anything. It’s good and bad coming back here, it’s good we can come back... there is a connection with this Hospital for the rest of our lives”**.

Katie asked the parents had they had any experience of music therapy. One of the mothers talked about how at her child’s school music therapy had been part of the curriculum, while other children had participated in music therapy through the Hospital, Very Special Kids and palliative care programmes. One member of tonight’s group spoke about how her son who was profoundly disabled had **“enjoyed music therapy at VSK. It was something he could do and he wasn’t going to miss that”**. Her son had a CD of children’s songs which was played to him each night, music **“a big part of his life”**. As we heard through the conversation, music was a large part of parents’ lives and had played a significant role over their children’s lifetimes even if these lifetimes were unbelievably brief. The children had loved music. Through the evening, as parents shared their connections with music we would hear of how some families had wonderful times when they danced to video hits on Saturday mornings. Right now, however, it was **“I can’t revisit that, I’m not there at this moment”**.

“Music”, Katie explained, “has the capacity to express difficult emotions and responses”. “It may be difficult to say with words, only, what these feelings are. In music such feelings can be expressed and shared. Where words are difficult to find music has the power to break straight into the heart”, Katie observed. Music can be engaged actively or passively, from listening to a CD to playing an instrument. Several fathers in tonight’s group were guitarists and we heard some-

thing of their guitar playing and its meaning as the evening unfolded. Listening to music, making music and songwriting were some of the ways that Katie named as vehicles for the expression, acknowledgement, exploration and integration of emotions, thoughts and experiences. Katie described how music can be used in various ways. For example, music may evoke memory. “Drum banging” Katie said “could be used to release strong emotions such as anger”. While listening to or creating quieter music may provide “an opportunity for relaxation”. The “back and forth” of music played between people may be a means to communicate. Music and music therapy have also been beneficial as means of pain management, Katie commented. She explained that the same pathways for processing pain are used to process music.

As Katie invited group members to reflect on music in their own lives and particularly to call to mind the songs that might have been important to them and their child. A father spoke about how his young adult son loved music and to play the guitar. The father now found listening to his son’s music **“soothing”**. There was a **“connection”** through his music. His son had planned to teach his father to play the guitar **“that’s the deal”**. Now that his son had died a friend of his son’s was going *to teach him*. In hearing the father’s experiences, Katie observed that “it is possible to learn music and experience music all through life”.

In continuing the exploration of this theme a mother spoke about how just after her son had died, in the early days of her grief it was **“hard to listen to any music...now I’ve changed I can listen it’s ok but it has to be his music and no one else’s”**. In contrast to his wife a father told of his initial feeling being **“the reverse I really wanted to hear his music”**.

As parents shared their response to Katie’s questions and music’s connection with their child a mother whose baby daughter had died within days of her birth spoke about the music how **“there was no time to share anything. But my father and my sister had each sung Over the Rainbow to her after she died. They didn’t know the other had sung it. I have it on an IPOD.... it’s nice to have and to hear. I’m**

connected to her... it's nice to have a normal memory to share. She went on to say Over the Rainbow has taken on a very special meaning for her now. **"It's something different now ...it's significant. I take that with me... it means a lot"**. And as Katie observed also for her "daughter's greater family". Music can create a bond between people. Over the Rainbow was then played at her daughter's funeral service.

Another song spoken of by parents in the group as being a part of the celebration of young lives was *Forever Young*. While a parent remarked Twinkle Twinkle Little Star **"that's his song now"**. Memories of songs included a little girl being **"very excited over Humpty Dumpty.... (playing it) got a big reaction. It had been acted out at school"**. Several parents within the group spoke about just how **"hard it is to hear children's songs"**. During the evening, parents in the group shared how from the time of conception their children had been listened to music and been sung to. **"He always listened to it (the CD player), ... he'd crack it if you turned it off"**. Some children had made music too. The group learnt about exciting keyboards that could be kicked with their little feet to make music. This brought some happy times during hospitalizations.

Katie remarked that there is something very "normal about music.... it's not set to a particular place but it can live on and continue". She noted, "the words overtime can mean something different to someone". A mother told of her experience of music in her grief. She said **"it's comforting... I listen over and over to it (a song that had been sung to her baby) brings back good feelings but also the angry and the sad ones. It's nice it's like there's peace ...it's a good thing apart from meeting and having her that was the best thing in my life"**. As Katie reflected "the good feelings can be felt, and also feelings of sadness". As another father said music **"comforts me"** echoing earlier comments **"I know if I put the CD on when I drive even if it's melancholy it feels good"**. Parents spoke about how they had found at different times a piece of music evokes different feelings. It isn't always predictable. In continuing to think about relationships with music a

father spoke about his connection with music through church music and playing the guitar. He used to play his guitar to his wife during pregnancy and in hospital through his son's very short life. Playing music to his son was something he had **"dreamed of doing"**. Before he was born their son would **"wriggle"** in his mother's **"tummy"** to his father's playing. His son's life had **"inspired me to play and to spend time writing songs"**. The father explained that he had found song writing, which he had recently taken up and something he thought he would never do, was **"incredible therapy for me"**. He described how music was a way for him to be able to **"express what I'm feeling as a man"**. His partner commented that his writing and playing were **"helpful for me to understand what his feelings were"**.

As parents reflected on the songs played at times of intimacy and the emotions and memories they bring, a mother said **"I need a pathway to it, I need to grieve this (playing music made this possible) it's good and important to feel it"**. Katie responded that music is often a way that people can "let it out. Music can be form of "support and comfort... it can touch but it can also be turned off when that's needed". Another group member said in her experience, music was **"trigger to remember... it can be hard but it's good at the same time"**. "Music" Katie said "can act as a way to gauge your own place within your experiences".

As we moved further into the time together, Katie asked the group about whether they would like to try out song writing or guided imagery. A father replied **"I don't think I could write a song now"** and a mother said, **"I need to relax"**. These two views seem to be the sense of the group so we went on to participate in the guided imagery.

Katie explained that during guided imagery we would stay in our chairs with the lights dimmed slightly and she would take the group through a gentle relaxation of the whole body. During the relaxation, parents were invited to think of a colour and to imagine that colour through and surrounding their body and then to bring to mind an experience with their child. She would then play a piece of music, which would last about 9

minutes and then from listening to the music's flow into parents creating a mandala. Mandala is a Sanskrit word which means magic circle or life circle. Katie said the parents' drawing with beautiful pastels could stay within the continuing circle which she had outlined on the paper or could move beyond the circle. The drawing would come from an expression related to the imagery. When the imagery was finished and the mandala created Katie suggested that parents write the date somewhere on the piece that they had drawn. Katie then invited parents to come back as a group and if parents felt they wanted to, talk about how the experience was for them.

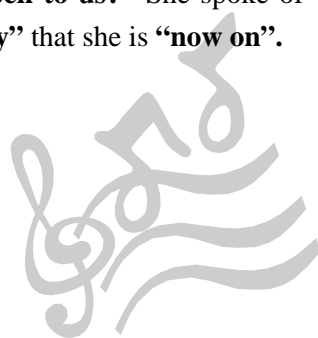
The piece Katie played, she was to tell us was Beethoven's Romance in F number 2. "The piece" she explained "has movement and complexity and intricacies within it".

Katie would say to the group that the mandalas would be individually reflecting parents' own experiences. Other people's responses to the group members mandalas would be "projections from other people, their points of view".

As Katie opened up the group to share experiences a mother talked about how she'd found it "**a difficult physical experience**". For her "**two colours were swirling together**" competing for dominance, space and attention. This was played out quite powerfully in her mind and on her body. In the process of the relaxation she decided to "**let it be what it would be**". "**Grief**", the parent said, "**is very physical**". "**There are points in which you want to vomit or you feel physically exhausted from crying**". She had a sense of wanting to draw the competing swirling colours but somehow also wanting to "**contain it**". Katie noted that "those moments that are inside aren't always positive or good but being present with it you can see it, maybe see it in a new way". At the very centre of her mandala the mother had wanted to place her daughter. She "**had to be right at the centre**", a feeling held by others in the group.

In describing her mandala another group member likewise spoke of the "**whirling confusion**" and yet within there was "**some gold that is breaking through**". After five years she was beginning "**to see light again**". She described how the process tonight "**built on other experiences**" that she had recently had where she'd been reflecting on her lifetime. "What's happening at the time matters" Katie noted in response "and will affect the experience". The mandala can "always be looked into more if that's what you want" she said.

With the discussion moving randomly around the group, a mother spoke about how "**there are lots of questions like the music there's highs and lows. There are more angry moments than sad. There's heaps of talk but there's confusion. We've got questions not answers. I had the physical pain of the C-section, the shock, the confusion, it shouldn't have been like this, why did it happen?**" Questions were also at the forefront of another parent's heart- unanswerable questions. She wondered if her son was frightened during his dying. These matters had not been spoken about. The focus was on living and hope. That was his choice, his way. Such questions were also shared by another parent who wondered if her newborn baby was "**scared by all that was happening**". Her questions were tinged with regret at not being able to reassure or comfort her baby. "**I should've been able to do that**". Events surrounding her baby's birth and as yet the lack of information available to her and her partner were causing additional suffering for the couple. "**Processes like the Coroner's mean I can't shut the door or move onto the next chapter yet. It stops me from moving on. She was taken away not our fault, you can't get your feet to where you want to be**". Later another mother whose baby son had died would share similar dilemmas and responses as she talked about "**crushing disappointment how could it happen to us?**" She spoke of "**being open to the journey**" that she is "**now on**".



Like **“a rollercoaster... like the anticipation of the music... we were expecting a healthy baby** were the words used by one parent to capture her experiences. This analogy was extended by a father who said **“there were ups and downs of feeling - the troughs. Little things bring you undone like photos”**. While for a mother in the group her *undoing* was the thought that she would never see her daughter’s children. **“I did hit the wall. There are stages. I try to take the negative things and make them positive but it’s really hard. It wasn’t something we did to her? There are people out there still doing their jobs... but we’ll have this forever”**.

From her drawing a parent spoke about **“the darkest valley”** but of now finding that faith was her **“greatest comfort”**. She thought the guided imagery and mandala have been **“quite a nice experience”**, she felt **“a nice cool breeze”**. Images of her son and times spent with him had been recalled and enjoyed through the relaxation and the music. **“It was a good process but a difficult one”**.

As we were to hear from other parents around the room, one father said that during this week he’d had **“a sense of being off on a path... it’s a different one than the path most others are on”** This was now reflected in his mandala. His comment was **“We have a profound view of life and what we are here for”**. In a similar voice a father reflected **“this (his son’s death) has certainly changed my views and priorities....I’m not materialistic....if there’s something I want to do now I just do it, it changes you as well as changes life views.**

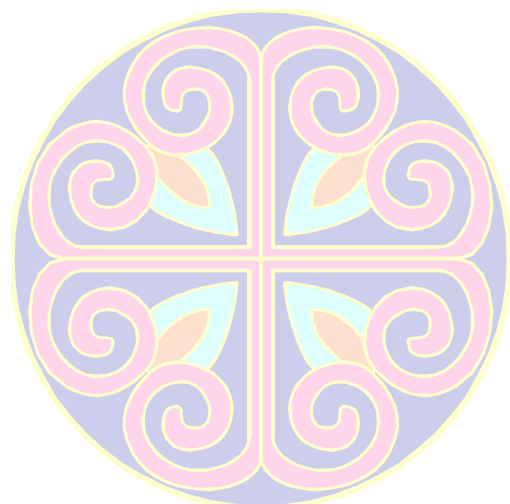
The sense of change was likewise expressed by a parent who spoke about her desire to follow a healthier life-style **“if that can happen to a little girl without warning what can happen to me. I have to be healthy for her brothers and sister that will come. I’ve put life into perspective. It was somewhat cloudy before”**.

From the parents’ comments Katie remarked that “the same piece of music can be a quite different experience for each person. With music and some time out it can

change where you are for a time”. For those who are grieving that can be supportive. Some parents chose not to speak about their mandalas and as is the nature of the group this was respected.

As we reached the end of this part of the evening we thanked Katie very much for providing a gentle, respectful space in which we could explore the meaning and comfort music can offer those who are grieving. Throughout the evening we were reminded of how connected parents and their children had been and were to music. The colours of the mandala also reminded us of the theme of this year’s Memorial Service, ‘The Colours of Life’, while linking back to the theme of last years service ‘Finding your own Rhythm’.

Before moving to supper Carol explained that she has been invited to contribute to a review of palliative and bereavement care services being conducted by a commonwealth government body. Carol very much wants to represent the views and experiences of parents who are bereaved through child death. Parent’s stories are particularly powerful in influencing decision makers and shaping policy. Carol asked parents if they had particular comments they would want to pass on. One of the issues that was raised by the parents in the August group was the inadequacy of bereavement leave **“three days”**. Captured by a parent with these words **“after six weeks I’d run out of money so I had to get back to work....I had no choice”**. Carol’s email address was given. However, parents can also write to Carol with their thoughts care of the newsletter or ring her at the Hospital.

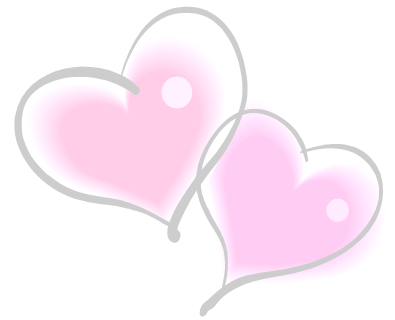


Straight from the Heart

This month we don't have a piece written by a parent or family member that we can include in the Newsletter so we are including this helpful reflection given to us by a parent in the group. Our thanks go out to her.

*'SOMETIMES THE RICHEST THINGS,
CAN COME INTO OUR LIVES FROM PLACES
WE WOULD NEVER CHOOSE TO GO.'*

Author Unknown but being searched for !



And from the hearts of brothers and sisters ...

On Friday 18th August, we ran our annual Sibling Bereavement Group, and 17 children joined in the activities of the day.

Our broad theme for the day, 'The Colours of Life', was taken from the RCH Memorial Service for this year. After hellos and a warm welcome, we set some rules for the group. These focussed on safety and respect. Children were encouraged *to pass* if there was something they didn't want to talk about.

We then divided into two smaller groups: one for ages 5-7 and the other for 8-13. Some younger brothers and sisters participated in the groups with their older siblings. The parents went to their own group where they helped with the symbols and decorations for the Memorial Service.

Each participant was given an activity and information book to take home with them.

Our first activity called 'Family Tree' is included in the book. This involved choosing different coloured and sized buttons to represent each child's family members. It was a good starting point for thinking about families, their brother or sister who died and for beginning to share their experiences with the group.

In the younger group, Dr Seuss's book, *My Many-Coloured Days*, was read to introduce the concept of linking colours to feelings. Both groups then each created a group mural representing the colours of their grief. The range and nature of feelings experienced was well-expressed in both groups, with dark and angry colours taking their place alongside delicate or warm shades and symbols. They clearly show how complex children's grief can be, too. These murals decorated the stage at the Memorial Service.

At the same time, the older group, after some more 'getting to know you' energetic games, used a 'Suggestion Box' to think about what was helpful, unhelpful and wished-for following the death of their sibling. The children's responses were meaningful and poignant. They gave an insight into some of the issues the children face. One especially notable theme was the unhelpful ways in which other children at school reacted. This seemed to highlight just how isolating grief can be:

*Some people didn't understand how it felt.
When someone didn't want to play with me and they were being really mean
to me and when my friends hurt my feelings.
When my friends say mean things to me about Mary [name changed].*

Having support from family, friends and community was considered helpful by most of the children:

*When I was helping my friends and they helped me too.
When my friends and family comfort me when I'm sad and thinking about
Simon [name changed].*

All the children wished that their sibling was still alive or that they had spent more time with them:

*I wish I could give my brother one more hug and say a real goodbye to him.
I wish that she didn't die.
One wish is that I spent more time with her.
I wish I could see my little brother again.
If Jenny [name changed] was alive it would be the best wish ever.*

The two groups then came together to make kites, in memory of their brother or sister. The children were very absorbed in decorating the kites and choosing coloured streamers. They seemed to have great fun and enjoyed sharing the activity together. We ended the day with a 'round the circle' ending ritual and certificate giving.

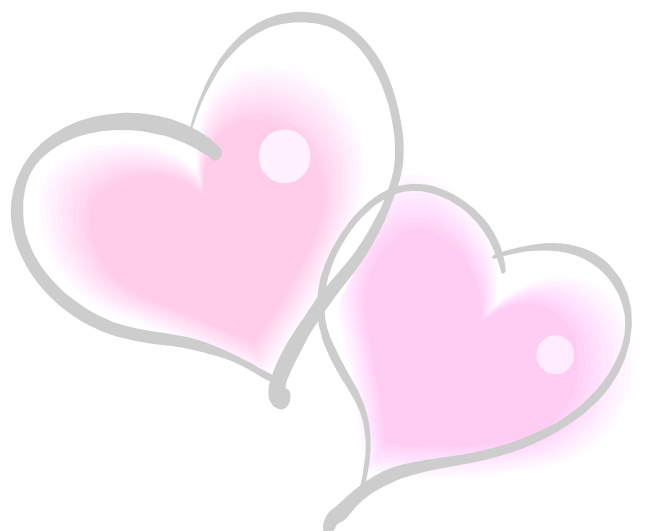
Hearing from brothers and sisters who are grieving was a rich learning experience for us and we appreciate the children's willingness to share their feelings and stories. Not only did they help each other by meeting with other children and talking together, but they helped us gain a better understanding of what children go through during times of grief. These are insights we will take with us into our professional lives and we hope this will help us to better support children experiencing loss and grief. We would like to thank the children again for their participation.

I liked the games.

*It was helpful because we could express our feelings, and everyone knew what we were
going through.*

It opened up my eyes to new things.

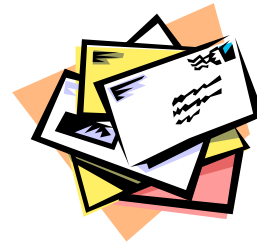
Hannah Ling & Elizabeth Jones
Social Work Students



Contributions such as poems, letters, songs, quotations from parents, grandparents and friends are most welcome in the Newsletters. Share your thoughts, experiences and questions with others who are bereaved.

Please forward them to:

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



Our letterbox is empty!

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

Thursday 21st September

7:30 pm – 9:30 pm

Seminar Room 2, 4th Floor

Front Entry Building

Royal Children's Hospital

Our guest will be Ms Maree O'Toole, Bereavement Services Coordinator, Royal Children's Hospital will explore the question faced by many parents who are bereaved: *Who Am I Now?* Maree who will be well known to many parents through her work over the years in the FBSP has asked if parents feel able could they please *"bring a photo of yourself from your childhood or adolescence to share with the group."*

Please join us for an evening of reflection and conversation

The newsletter is always a team effort. Thank you to the parents of the Parents' Bereavement Support Group, Katie Lindenfelser, Carol Quayle, Jane Miller (Chief Social Worker), and to our able and dedicated Administration Team Aleisha Desmond, Carly Burnett and Rebecca Welsh for their enormous assistance with the creation of the newsletter.



Jane Sullivan
Author & Editor