

# PARENTS' BEREAVEMENT SUPPORT GROUP



Social Work Department  
Royal Children's Hospital

JULY 2006 NEWSLETTER

*Welcome to the Newsletter of the Family Bereavement Support Programme. Through the newsletters and groups we hope you will find support, resources and connections with others to help sustain you as you grieve for your child.*

## ***“Through Young Eyes” - The experience of children and young people living with grief***

We warmly welcomed parents who joined the July group. In welcoming the parents we acknowledged their children and the experiences they had shared together which had led them to the group. We especially acknowledged the impact that returning to the Hospital or joining the group for the first time may have on parents. The Parents' Bereavement Support Group offers a time for parents to meet with others who are grieving for a loved child. It's a safe place to share and explore experiences and ways of living with loss. Parents are invited to participate during the evening in ways in which they feel comfortable; to talk as little or as much as they feel able. If the need arises parents can *take time out* from the group. The groups are open to parents to come whenever or as often as they feel it is helpful to them.

Notes without names are taken during the evening to help create this newsletter.

Carol and Jane can meet with parents in person or talk with them by phone if there is something they would want to talk over outside the group setting. They can be contacted through the Social Work Department (9345 6111).

To explore this important topic the group was joined by Ms. Liz Wynne social worker in the Oncology Social Work Team, Royal Children's Hospital. Through her role in the Oncology Unit, the social work on call service and her experiences in the community Liz has worked closely with young people. She has helped to support and resource children and adolescents living with change, loss, trauma and grief. Before joining the Hospital, in her previous role as a community development officer, Liz developed a support programme with local groups for those who were

bereaved through a number of circumstances. Despite this background and context Liz emphasized that she had





come “not in an expert role” but rather to share some of the many insights that children and young people have given to her over the years. Liz’s understanding about the grief felt by young people has recently been expanded by her experiences overseas through Camp Sunshine. Camp Sunshine in Gasco, Maine (USA) offers camps where whole families who are bereaved can come together in a comfortable environment. Families have a dedicated supported space at Camp Sunshine in which they can access, process and honour their grief. Liz noted that the young people she had met at Camp Sunshine had given their permission for their thoughts and stories to be handed onto others. Their hope is that this will aid understanding and support for young people who are grieving. Liz expressed her gratitude for the Hospital Scholarship that had made her time at Camp Sunshine possible.

As the evening began, Liz said to the group that she hoped parents would not feel that they were “on the spot at all”, yet to comment and question as they felt able. Much of what Liz would go on to speak about, she explained, could relate to brothers and sisters and also to cousins, school mates and friends of the children who have died. Most of the themes of the discussion could also *equally* be applied to brothers and sisters who were born after the child had died. This was especially relevant to underscore as several parents in the group were grappling with questions of how to include their child who had died in the lives of their children yet unborn.

From listening to young people who are bereaved Liz has learnt that much of their experience with grief mirrors that of their parents. Their needs for

understanding, encouragement and support are similar to those of adults who are bereaved. In the unfamiliar world of grief young people, like their parents may be challenged as to how to understand themselves. Echoing through young peoples’ stories are issues of support, family and peer relationships, guilt, memorializing and finding meaning. While many of Liz’s comments related especially to *children aged eight years and up*, there was a sense of relevance for those of all ages. During the discussion Liz would reflect that grief is “a whole family experience, everyone in the family is affected ...somehow it makes it easier (for young people to manage) if they can see it like this and not just something one member went through”.

To further set the context for the evening’s discussion Liz spoke of the inherent sadness in a child’s death while at the same time recognizing the importance and need for parent’s to “recreate the celebration of your child”. Later Liz would say that in our community child death is “not common but that’s the *reality*” for parents present in the group and for their living children. The meaning, confusion and isolation that can come from such a uncommon *reality* make it imperative for grieving families to have the support they find helpful. “You are different from other people. As bereaved people you are unique and special” Liz reflected.

From the outset and through the evening’s discussion it became clear that communicating and explaining, as best parents can, is the foundation of supporting young people who are grieving. This communication needs to be ongoing and change as the child grows and develops. Liz gave the example of how explanations of concepts such as crema-

tion may need to be revisited as children grow older and their questions change. “Children at 5 or 6 years often think that they don’t understand and when they are older they will. (Their parents may think this too) But when they are older it’s still hard”. No matter what the age, however death and especially the death of a child or adolescent is always difficult to comprehend. The pain is not less when the child becomes older “it’s there for life”. In reflecting on the death of a child a father said, **“with an older person history is lost but with a child you always wonder what could have been done”**.

On the subject of clarifying whether children’s questions are specific or general can avoid the possibilities of parents providing too much information. Amongst the most common questions that bereaved children over the years following their sibling’s death ask, Liz has found, are ‘Will they know who I am? -How old will they be?’ As Liz went onto explore the answers given by parents come out of their beliefs and values. “Any thought you may have irrational or not your child would have had it”, Liz suggested. Liz has noted how it can be useful for parents “not to block their thoughts”. Instead to think over such questions and then be prepared to respond honestly to their living children in ways they “sit comfortably” with their own views. Throughout the evening Liz also encouraged parents “to give answers they (the children) were safe with”.

“Life stops but they (young person) keep living.” Children and young people, following the death of someone they love or someone close to them, Liz said, “may feel as if they don’t have control over anything. They don’t have control over death. There is nothing that they can control... They may feel scared”. With the death of someone close to them

brings “a new level of understanding” for children and adolescents. It can be a harsh way to find out about life. From young people Liz has been told how “the fear of the future may extend... not only for themselves but for their own children”. Recognizing and responding to these fears is a significant, early step. Creating some sense of certainty and meaning may take time.

With the death of someone close to a young person, Liz has seen how a particular wisdom and discernment about what is truly important in life grows. This is reflected in how young people who are grieving will decide whether a friendship is good and worth investing in. Relationships, which are “wasteful of energy”, will often be *dropped*. This insight also rang true to parents’ experiences. As parents in the group agreed, through grief, some friends are lost, while some are gained for life. It can be surprising to see who falls in which category. For some children and young adults it may appear they are not grieving because they do not seem to be talking (as they are not talking to their parents). What Liz and others have also come to understand is that young people may be talking to other people of significance in their world. For example another young person, other relatives, neighbours, friends or teachers may be a great source of support. Children and adolescents, however, may not talk to their parents about their brother or sister who died because they are “protective” of them. They don’t want to upset them. Children will tell them what they think their parents can manage. One mother commented that her adult children **“they don’t talk about it (their sister’s death to her) at all”**.

Liz has heard from children how as time goes on they work out when it was a good time for them to talk to their parents. They had



learnt that if their parents were upset or angry that was not the time to raise questions. However Liz has observed that if parents explained what was happening for them the grieving child felt less confused and somehow *better*. It can also open up an important conversation. A mother spoke of an instance where her young preschool son had asked if she was thinking of his sister. He had read this from his mother's body language. The insightfulness and perceptions of even very small children can be astounding. It may be helpful to provide a context in which there is some distraction such as an activity or driving in the car where the conversation does not feel so intense to the young person. Many young people, Liz noted, may "block" their reactions for a time, perhaps for as long as a year. This can be very confusing and troubling for their parents. During the conversation, one mother had observed that her living child might not **"say it outright, they will say it (how they are feeling) in other ways"**. Providing a less stressed environment to talk perhaps while having fun again is important. Again the message "still enjoy life" needs to be highlighted. In listening to children and teenagers, Liz feels that they need also to be given the clear message "it's ok to be happy ...we are so lucky that we had this child".

As is often the experience of grieving parents, for young people in grief there is a sense of bewilderment and lack of purpose or point. From her time with young family members, Liz believes having parents genuinely acknowledge their child's confusion and their own uncertainty about life can be paradoxically reassuring. For the most part, children want their parents to be honest and tell the truth about issues of meaning and spirituality.

For the most part bereaved brothers and sisters feel that their sibling has "not just died". They need, Liz has concluded someone to let them know "it's ok to think that in some way their brother or sister continues to exist". There is **"constant conversation"** between brothers and sisters, Liz remarked. *All* bereaved siblings, she has met, spoke to their brother or sister who had died. *All* had a sense that they were understood by their brother or sister. As one mother remarked **"I think about her (her daughter) all the time, constantly I miss her all the time so why wouldn't he (her young son)"**. In response, a father commented **"It's not our belief that he died and that's it, an ending there... He's always there"**. He went on to talk about how his young daughter talks regularly about and to her brother. She perceives him as being **"in her heart or a star a rainbow in the sky"**.

Exploring this theme a mother commented how young children are frequently uninhibited in their responses. A parent said **"death doesn't stop them talking, they're not conditioned by society"**. Another group member reflected **"Our community sanitizes death and others get cranky when you are talking about a child who's died"**.

The support of peers, who from their life experiences shared a common bond, was one of the most highly valued sources of help for young people. Liz emphasized that children's grief like their parents' is "unique", however, the feeling of closeness with others who have gone through similar experiences is sustaining. "There is no comparison with other sources of support... knowing you're not the only person" is very helpful to young people. Although Liz also said to the parents "don't panic if your child isn't in a group".



Once more paralleling their parents' emotions and responses, Liz considers all children who are bereaved at times have feelings of guilt. Guilt has been discussed many times in the parents' group. It is a powerful emotion. Through her time at Camp Sunshine Liz saw how children and adolescents were able to talk to their parents about their feelings of guilt. While at "a level of logic" they knew that neither they nor their parents were responsible for their brother or sister's death they still carried the load of "why not me". In listening to families Liz has seen how, where there is openness of parents and children to acknowledge these feelings a healing conversation can begin. In a related issue Liz has learnt how it is very meaningful for bereaved siblings to know that their brother or sister did love them. Parents, Liz feels, have a crucial "role to play" in removing any doubt the living child may carry. In exploring the subject of guilt Liz commented that for parents an additional burden may be that they have not been able to prevent their child's death and aren't able "to fix their living children's grief". Parents have shared how they may be *intensely frustrated* if they feel they cannot help one of their children. Both parents and siblings would "swap places" with the one who had died if that was possible. Brothers and sisters, Liz has seen often carried feelings of regret not only about their sibling's death but may have regrets about how they behaved towards them during their lifetime. "How can you go back to fix it?", Liz asked.

Like their parents children who are bereaved make "all sorts of promises to be nice and good". Then further guilty feelings may come from feeling "they've let down their siblings when they are

themselves" *and not good and nice*. This is complicated even more by siblings' perceptions and remembrances of "only the good things... they don't remember the bad things at all ...no arguments only the good things they've done. Liz emphasized the need of young people who are bereaved to remember "in real ways their brother or sister". "Young people" Liz said "naturally go for the good". Yet having a brother or sister who is viewed as perfect and without fault can create all sorts of difficulties and expectations for their living siblings. "**Good, beautiful, cheeky little boy**" expressed one father's feelings about his very human and real young son.

"There is no day that goes by where you don't have a milestone... leaving the house is a milestone" Liz said to parents in tonight's group. So too children have their own milestones. Certain times or occasions in a family's life may hold a private meaning for brothers and sisters. Liz spoke about a child who always wanted her brother to begin prep so that she could show him around, and the loss when the older sibling's death has meant the younger child is *on their own* at school. Liz wondered whether in such circumstances it might be possible to use other members of the school community to act as a friend or mentor or to give the bereaved sibling a special role or task. Liz described how there may also be some social contexts where, with imagination, it is possible "to revert to their past role or position in the family". For example "to recreate an environment" of being the *youngest, middle or the oldest* for a time.

Liz has heard from young people that returning to school, from the young person's point of view, has



been a mixed experience. For some it gave a sense of “normality” but for others it was not a good time. This seemed to mirror parents’ experiences of returning to work.

One very supportive way young people may have to comfort themselves is music. Liz emphasized that adults should not underestimate the power of music. Music is a way of processing and expressing feelings. Music can evoke memories. (As an aside our guest for the August Group will be one of the RCH Music Therapists). For example Liz described how certain pieces of music might lead to recollection of sensations and images, even smells and sounds, which are meaningful to the young person. Of particular note Liz has seen that whether it has been a sudden death or a death that has come after a long illness that “music is instantly helpful... Comfort is not in themselves but in the music”.

In thinking further about what is helpful Liz described how very often many brothers and sisters had a possession of their brother or sister or had taken up one of their values, behaviours or causes. From ideals to having teddy bears and socks to working on a special project there seems to be something very supportive about this form of connection with the person who has died. Almost every young person that Liz has come across who is bereaved wants to find “something positive” out of the death. Young people may not always know what they can do or have the means to enact it but the desire is there. This is where the creativity and understanding of parents can come into play! For example parents can help their living children to work on a cause that was close to the sibling’s heart or fundraising or research into the disease that caused their death. Creativity was also useful when think-

ing, as several parents in the group, were of how to ensure that their child who had died would be a part of the life of their yet to be born children. As Liz observed “you can bring the past into the future”. Whether it is by adding pictures to family photographs, handing on toys or belongings, making a quilt together, or talking about the child who has died, there are ways to highlight the place that the child who has died holds in the family. A member of the group was thinking of her life with her new partner and the children that in the future she sometime may have with her partner. How would this affect the remembrance of and connection with her son who had died? Her partner and other children will not have known her son and yet her son will always be a part of her. “Where you go, he goes” Liz suggested. As the mother concluded, “**we’re a package deal**”. One mother shared her experiences with her now adult child. She commented how children as “**they grow want to know about you... it’s like the Spanish Inquisition**”. Her thought was that in the process of telling the family story the life of the older child who had died can be recalled. The sense of the group was that parents’ “**gut instincts**” are usually good and it is valuable to follow these in caring for living children.

Similar to the concerns expressed by their parents, grieving children and adolescents might worry that the “child who has died might slowly start being forgotten”. Young members of the family may have all sorts of ways to ensure that this doesn’t happen and these may be known only to the young people themselves. Some in tonight’s group encouraged their children to use “**the present tense**” when speaking of their sibling. This emphasized their continuing presence in the family.

Another worry for children and parents with the death of a loved one may be of losing a sense of control. From 11,12 and up a concern of older children is that if they cry they might lose control and *never cope again*.

Many times, people around families who are grieving may not ask or speak about the child who has died. This can be very frustrating for families. Liz gave the example of a young student who in classroom morning *show and tell talks* wanted to speak about her sister who had died but the teacher would cut off the conversation. The girl approached the teacher and said that “she loved to talk about her sister but it is hard to explain”. From then on in the class the girl had the opportunity to talk about her sister and it was a good experience. Parents may be able to support their children by letting teachers and others in the child’s world know that their child wants. In a similar vein, a mother remarked, **“I felt I needed to talk about (her son) all the time, I let people at work know... it’s ok ask questions, he’s a part of me”**. Although as one father responded often in work and other settings **“you’re helping to comfort them (other people)”**. The feeling of the group was frequently parents who are bereaved have **“to educate others”**. This is not always easy. From their comments, parents worked out whether it was **“worth it”**. This depended on their social context. For example was it someone they would never meet again and whether they were **“feeling exhausted”** and **“on a bad day”**. **“You can feel too tired to teach”**. One mother talked about her extended family **“they don’t talk ...we have no support”**. With such a situation Liz pointed to the value of being part of a support group where parents meet with others, listen to their stories, are able to speak about their

child and can have their experiences recognized.

Another mother shared her reflections six months after the death of her child. She had found that **“there are points in which you can block it out ... there’s an ebb and flow ...no timeline”**. One of her friends explained that to the mother she **“naively”** thought that over time the mother’s grief would diminish and had come to realize that this was not how it is. The friend was able to honestly and sensitively share her insights with the mother. This meant a great deal to the mother.

As thoughts turned towards what parents had found was helpful in their family, Liz asked parents in tonight’s group whether their families had particular rituals. A father spoke about how he and his partner **“light candles each night”**. Several other parents in the group found lighting candles a source of comfort. Knowing that other members of the families or friends light candles at significant times was also experienced as helpful for parents. Birthday parties and other celebrations at gravesides were mentioned by parents as helping to sustain them. Although as one parent commented **“it’s hard for friends to understand what you are doing”**. Liz suggested that parents ask their children how they would want to commemorate or celebrate a particular occasion or time.

During the evening members of the group were invited by Liz to reflect on the family dynamics, roles and positions, which had changed with the death of their child. We heard that some changes had been monumental and some more subtle. There were changes from being the younger to now the oldest, the only child or the one boy in the family and for parents with the death of their only child brought the loss of being a caregiver.

The complexities of experiencing a loss in pregnancy were shared with the group by a parent. **“It’s hard to explain ...to find the words I have two beautiful boys in heaven that’s enough”**. Another mother asked **“do you have to say they are dead?... I say I have two children”**. Once again the message of the group *was it’s up to you it’s what you are comfortable with at the time*. For as one mother said, **“if it’s an incidental meeting on the day and I am never going to see them again I may not tell the whole story... it changes moment to moment”**.

**“I haven’t changed his room I don’t like anyone going in there. It’s a mess”**. Several parents in tonight’s group were facing issues concerning their homes. Whether to sell homes, or to change a child’s room into another type of room such as a family room or den were amongst the dilemmas. One parent, two years after her child’s death, in commenting on her child’s room she said, **“Nothing has moved”**. Once more the group felt their decisions around the room were very personal. Liz advised only “one caution”. She recommended “not getting rid of anything, don’t do anything permanently... maybe have a trial. One mother said there were days where **“I feel definitely able to do it (sort out her child’s room and clothes), the next day definitely I’m not ready”**. One couple was exploring the possibility of using a medium to find out what their son would want for his room. They were hoping he might be able to guide their decision-making.

As we came to the end of this part of the evening a father asked Liz whether there are programmes like Camp Sunshine available in Melbourne. Some community organizations have retreats and weekends for parents and day activities and sleepovers for children and adolescents. We didn’t think whole family camping experiences however were available. We would be interested in hearing from parents if they know of such programmes. Liz explained that it might be possible for a family to create as it were a mini version of Camp Sunshine by planning together a weekend of special activities and times. This would need to have the willingness and support of all family members.

Before moving to more conversation over supper Liz wished group members well and concluded with the gentle encouragement “remember the beauty of the children”.



# *Straight from the Heart*

*Our sincere thanks to Mrs. Marilyn Di Pietro Jessica's mother for sharing her poem 'A Baby Saying Good-Bye To Its Mother'. Expressively written from a child's perspective, this poem speaks of the love between baby and mother and how connecting with that relationship can offer encouragement and comfort. We are honoured to include these touching words in the newsletter.*

**In memory of  
Jessica Silvana Tzaros  
06.03.2006—11.03.2006**

“My name is Marilyn Di Pietro. My baby Jessica Tzaros died on the 11.03.2006 she was born on the 06.03.2006. We had little time with her. I would like you to read what I wrote and if you like you can put it in the newsletter to help other mothers.”

## *A Baby Saying Good-Bye To Its Mother*

It took love to create me, and when I arrived you were excited to see me.  
Now I have died don't be sad,  
Just remember that I am glad,  
That you had me for the nine month's trial. The times I kicked to let u know I was near.  
And now I'm gone but not Forgotten  
Ow Dear mum, I love you Rotten.  
Just admire the time we shared.  
I will be your guardian angel from up above, making sure you can go on,  
For all I want is for u to create another baby that awaits.  
To look like me in some way,  
To let u know that I'm still there with all the Love u both will share.  
Please mummy don't give up  
Cause all that Love is just above.  
Close your eyes and picture me there cause I'll be smiling at you everywhere.

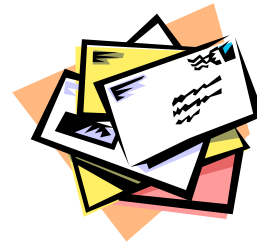
Thank you mummy don't be sad cause I will see you once again.



Contributions such as poems, letters, songs, inspirational pieces, and quotations from fathers, mothers, grandparents and friends are most welcome in the Newsletters. Please share your story, thoughts, experiences and questions with others who are bereaved.

Please forward them to:

The Editor  
Newsletter, Parents' Bereavement Support Group  
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Royal Children's Hospital  
Flemington Road  
PARKVILLE VIC 3052



*Our letterbox is nearly empty!*

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

**Thursday 17th August**  
**7:30 pm – 9:30 pm**  
**Seminar Room 2, 4th Floor**  
**Front Entry Building**  
**Royal Children's Hospital**

Our guest will be Ms. Meagan Hunt, Music Therapist, Royal Children's Hospital. Meagan has used music therapy in hospital, rehabilitation and community based settings in Australia and overseas, to help support children, adolescents and adults experiencing loss, trauma and grief. In the August group, Meagan will facilitate an evening of listening and responding to music, song writing and C.D. creation. The theme for the group is:

***“From Thoughts and Words into Music and Song”***

*Come and be part of the August group*

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



**Jane Sullivan**  
**Author & Editor**