

# PARENTS' BEREAVEMENT SUPPORT GROUP



Family Bereavement Support Programme

Social Work Department  
Royal Children's Hospital

**APRIL 2006 NEWSLETTER**

*Welcome to the April Newsletter of the Parents' Bereavement Support Group. We hope the groups and the newsletters offer you continuing support as you connect with the experience of others when you both remember and also grieve for your child.*

## **“Going On: Not Getting Over - Grief, Trauma and Memory”**

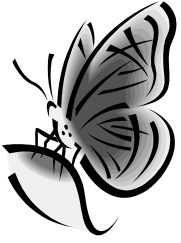
Welcome to this report of the April Parent's Bereavement Support Group. On a cold and rainy night 10 parents came to share the memories of their child, the depth of their grief and some things they have found comforting in their journey. Carol welcomed the parents to the group and acknowledged the courage it takes to return to the hospital and be a part of this group. She especially welcomed a couple who were coming for the first time tonight and expressed the hope that they would find the group a safe place to share their experiences or to choose to be silent. Carol reminded the group that they should feel able to take a break from the group if they needed to. The group is intended to be a confidential space and Maree O'Toole was taking the notes for the Newsletter whilst Jane Sullivan is on leave. The Newsletter includes quotes and stories from the parents without using identifying information.



Carol welcomed Jon Stebbins to the Parents Bereavement Support Group. Jon is a

psychologist as well as a bereaved parent. His son Matt suicided in 1987. Jon described how this tragedy changed his thinking about a lot of things. At the time he was teaching student welfare coordinators. Jon described how, “as a man he went into his head” and went back to work very quickly. He became more interested in the areas of grief and bereavement and he chose to do a doctorate in loss and grief in order to understand it more. He is now engaged in research for ‘The Compassionate Friends’ asking bereaved parents about the financial cost and impact on relationships when a child dies. Tonight Jon planned to offer some of the insights he has gained about the grief journey through his studies and personal experience and to provide an opportunity for the parents present to add their experiences to the discussion.

Jon began by asking the parents present to share something about their child and the circumstances around their death. Three fathers and seven mothers shared some of their story.



The children ranged in age from 8 weeks to 16 years. Several had died after illnesses complicated by their disabilities, others had been diagnosed with cancer and one had died in a car accident. For most parents it was at least a year since their child had died and one father commented, "After a year it was all going to make sense – I was almost expecting something to happen at the stroke of midnight." Another couple related how the death of their baby was hitting them harder now (6 months post) than it did at the time when they felt 'almost detached'. Jon acknowledged how often our system goes into shock for at least 3 months and sometimes as long as 8 months. This can have a numbing effect until the system returns to normal and we feel the pain. Some parents experience the second year as being harder than the first. One mother whose child died over three years ago was returning to the group just prior to what would have been her daughter's fourth birthday. She said, "it does get better, the distance between cries gets longer but the anniversaries are still hard".

Jon spoke of how complex and unique grief is. Its very complexity helps explain some of the feelings and thoughts we experience and why our progress seems so slow and confusing at times. He went on to outline some of what he has learned about grief through his study and personal experiences.

"First of all, we now believe that there is within all people an innate, automatic, unstoppable drive to understand or make sense of or give a meaning to new experiences. When our child died, whether we like it or not, immediately this drive to understand the experience comes into force. We can block it for a time, and most of us do this for at least short times, because we need

time out to regroup our energies. Men are particularly good at blocking out. But inevitably the pressure to keep searching and seeking answers re-emerges. Some people work very hard to totally block out their loss and pain. This is where real problems emerge. It takes an enormous amount of energy to keep the block in place. So these people are usually continuously exhausted, or the pressure of the drive will come out in stress illnesses. So, painful though it may be, if we face our loss and pain, in the long run we are better off."

One mother asked Jon how long people could block for. His reply was some might only block for 3 months but what they are holding back is of such intensity that they break down whereas others might hold a block for years but it takes an enormous amount of energy. Jon added that the block might not always be a bad thing as it can give people some time to rest.

Jon spoke of the complex and unique aspects of grieving. These include:

- ◆ An infinite range of feelings - such as hate, love, anger, fear, concern... - with time they affect us and their intensity varying from moment to moment.
- ◆ An infinite range of thoughts, also varying from moment to moment in their intensity and time they engage us. Some might think "I could have done more", for many weeks or months whilst others may move past this thought in a week.
- ◆ There is also a range of images that we must deal with - especially if the dying and death was traumatic.
- ◆ We also have a wide range of relationships that we must re-establish and some we have to 'let go' due to disappointments..

So it is no wonder that our 'recovery' is slow, confusing, up and down, and leaves us

exhausted, distracted, overwhelmed. People who think you should be moving on after 6-12 months have no idea that you are trying to handle something so big. We often have to fight very hard just to get a short time to ourselves to think about our child and recall comforting memories.

Jon explained that an additional complication to the grief process is the interaction between grief and trauma responses. This is only starting to be explored in the research and theory about grief. Jon outlined what his understanding of this is.

‘*Grief* is a process of re-establishing a new relationship with our dead child. A relationship based on storing up memories - thoughts and feelings and images that we can take with us into the future, and walk comfortably alongside. Grief is a process of wanting to recall, store up, engage; a movement towards. *Trauma* involves facing and dealing with awful, frightening, even terrifying and horrendous visual images, thoughts and feelings: images of our child in pain and not being able to take the pain away, or of watching the ravages of some diseases. Flashbacks are these traumatic images intrusively pushing into our minds. Traumatic reactions activate another powerful internal drive. A drive to protect us from danger - in this case emotional and mental danger. Therefore, trauma is a process of avoiding, blocking, shying away from. The process of grieving - storing up good memories - is therefore slower when trauma is involved- as is always the case when we have a child die - because there is this constant clash between two powerful inner drives.’

In response to Jon, one father described his struggle to remember anything beyond the traumatic memories. He asked Jon how long it takes for the happy memories to replace the

traumatic ones. Jon found it difficult to give an absolute answer to this question but said that he had stopped counselling anyone for 18 months after the death of Matt, which is some indication. He said the traumatic images come back every now and then but there are now big gaps in between and they don’t have the power that they used to. One mother in the group described how four years after the death of her child she still has trouble coming up with happy memories as she keeps returning to the trauma of intensive care. The painful memories were shared by a couple that had memories of their son being, “more an exhibit than their son”. They were unable to touch or hold him as he was connected to so many tubes. The process of re-engaging with the happy memories had taken a full four years for another mother who described how her colleagues started commenting on the fact she was smiling when she talked about her son. Jon noted that it takes some time to recognize that you can be happy and sad at the same time.

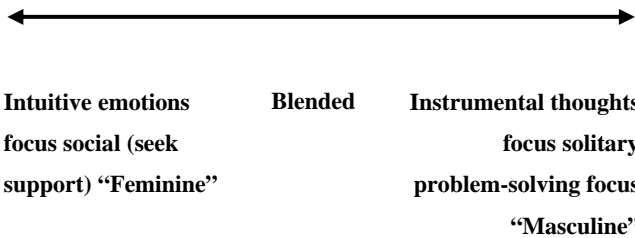
Sometimes actively engaging in developing the positive memories can be helpful. One couple described how they have asked their daughter’s school friends to write stories and add them to the stories and photos on their memory table. They are also revisiting all the places they went with her and adding some stops at wineries along the way. There were some smiles around the room as they added, “the wine also helps!”

Jon moved on to an exploration of some theory and research relating to gender and styles of grieving. He drew the diagram below on the board and explained the intuitive end as being more often a feminine approach. These are people who do their grieving by talking to others to get some understanding. The instrumental end is usually a more masculine style. It involves addressing



issues such as, “who is going to get the children to school?, or bring the money in and how will we go about organizing a memorial?”

**Martin & Doka (2000):**



Jon asked the parents present, “where do you see yourself?” on the diagram. The answers varied not just based on gender. One mother described how as a single parent she has been forced to be up the instrumental end and is only recently engaging in a more intuitive approach, which probably fits better with her nature. “I didn’t have the opportunity to just fall apart” said one father who had to get back to work. A mother described how her husband started a new business soon after the death of their daughter and some time later was hospitalized with spasms and was diagnosed with a form of chronic fatigue. Several parents agreed, “Everyone needs the chance to fall apart”.

Jon described a study of bereavement interventions that found that men responded best with emotion focused therapy and women with problem focused therapy yet given the choice they each would have chosen the opposite intervention group (Schut, 1997 in Parkes, 2000). This suggests that we choose the path that is familiar to us but at some stage we need to find a balance. Men are often limited in their choices by their socialization. In the primary school yard if a girl cries she is comforted but if a boy cries he is taunted. There are many social, cultural and economic expectations that limit a man’s capacity to be emotionally focused.

Jon asked the group to reflect on what this might mean for the couple relationship. One couple described how they take turns in supporting each other. Their experience of parenting a daughter with a disability prior to the death of their baby has meant they had already developed ways of bouncing of each other in difficult times. Jon noted that sometimes it can be really difficult to support your partner when you are both feeling so depleted. He related how when Matt died, David Treloar, an educator for Tobins, advised him and his wife to give each other permission to have someone outside that you could call on 24 hours a day for support. This advice greatly helped him and his wife when both were in need of support. One mother described how she and her husband feed off each other but she also has a close sister and he a close brother to talk to.

The conversation reverted to the differences between males and females in grief. One father suggested men are better at putting things in boxes and gave the example of when starting to experience some emotion at work he can tell himself, “Now’s the time to work, later I can fall in a hole”. “Sometimes you have to hold in the emotion at home too, in order to parent the other children”, was the response of a mother in the group. She acknowledged that it might be easier to find a hiding space for a short time at home. Other parents could relate to the pressure to keep things going at home. They are forced to get out of bed to get children ready for school and others are telling them, “Pick yourself up”.

The expectation of others was another topic that prompted much discussion. One mother related how difficult she finds it when people say, “You should feel happy with what you have got.” She assured us she is happy with what she has but the implication from this statement is she cannot be unhappy that her baby died. For a father in the

group it was the lack of response from his male friends that disappointed him. They never mention his daughter's name and quickly change the subject when he does. His experience at work was similar with only one person he worked with acknowledging that his daughter died in the year since her death. In response to this a mother mentioned a workshop she had been to that related the way you relate to grief being associated with your childhood experiences and attachments. She found this a very helpful way of understanding her own grief but also of understanding how people respond around her.

Opening up to others about how she is feeling was described by one mother as an "honour". When she cries in front of others she reassures them not to be embarrassed as she is honouring them with her trust. Many parents were grateful for particular people in their life who offered support. For many it was their husband or wife, for others a neighbour, a sister or the wife's friends. As Jon said, inevitably because grief is so unique you grieve alone but this doesn't mean you have to be lonely.

The conversation moved on to a reflection on the shift in perspective that occurs when you experience the death of your child. Two participants in the group were pregnant and one described her conversation with the liver specialist who looked after her daughter. She went to see him recently and he reassured her that her daughter's condition would not be repeated in the family. She stated, it is one thing to know intellectually but another to know emotionally. All the parents present could relate to the anxiety that comes with experiencing the death of a child. They said, "it's opened my eyes to how delicate life is", and "I realize I am not untouchable anymore". For one mother this

added to her anger at watching a friend smoke throughout her pregnancy. It is difficult to watch others taking risks with their children's wellbeing when you have suffered the terrible loss of your own child.

The issue of guilt was raised by a mother who had been driving with her daughter when the accident that resulted in her daughter's death happened. For her this is an incredibly intense and painful aspect of her grieving. She has found the response of others has added to this burden. Her way of handling it is to throw herself into her work. Jon reflected on the common experience of guilt amongst bereaved parents and acknowledged how painful this can be. He said, "As parents we are supposed to look after our children and their death is something we have been unable to protect them from". One father stated that their biggest fights as a couple have been over guilt. He has been frustrated with his wife's expressions of guilt and tells her, "You cannot hold yourself responsible". His wife reflected on how it can be "so hard to *hear* that when you have the feeling". Another mother had found it helpful when her husband suggested, "swap yourself with your child would she want you to feel this anguish?" She said, "I have come to believe that I let her go and released her from pain". This belief was echoed by another mother who described releasing her daughter in the faith that she would be looked after in heaven.

There were other things that parents felt guilty about like not being able to protect the other children from the grief they were experiencing and being the ones still alive when their child has died. Jon stated that when we feel guilty we are not giving ourselves permission to make mistakes. We all know, "I would not under any circumstances hurt my child".

As the formal part of the evening was drawing to a close Jon summarized his thoughts by encouraging parents to be kind to themselves and not to expect too much, to plan time to rest and to focus on simple good memories and to talk and share with others. He said, "there is something magic in sharing with others" and he shared with us this quote from the latest compassionate friends newsletter:

*'Don't try to destroy a beautiful part of your life*

*because remembering it hurts.*

*As children of today and tomorrow,*

*We are also children of yesterday,*

*The past travels with us,*

*And what it has been makes us what we are.'*

Rabbi Earl Grollman

Carol thanked Jon for sharing his knowledge with us and invited everyone to continue their sharing over supper. This opportunity was enthusiastically embraced and there was much talking, sharing of photos and comfort gained in the knowledge that these people can listen and truly understand.

*Jon also invited members of the group and the readers of the Newsletter to be involved in the research he is conducting for The Compassionate Friends. The research involves a questionnaire asking about the impact on relationships and economic impact for families who experience the death of a child. Some families may be asked to be involved in a 45 minute interview after completing the questionnaire. If you would like to be a participant in the research or would like more information you can contact Jon Stebbins or Trevor Batrouney on 98884944.*

## **We Need Your Opinions Again!**

Dear Parents,

This month I have continued to work on the hospital guidelines for when a child dies and they will be circulated through the hospital over the next 6 weeks for staff feedback. We have also been talking with the Auxiliaries Department about assisting us to develop bereavement care resources for families. They are planning to ask all the auxiliaries associated with the Hospital to donate a proportion of their funds towards bereavement care. This will assist in the purchase of memory boxes and albums, disposable cameras, candles, some special children's storybooks and information booklets for children and parents. Please let me know if you have any ideas on what we should be providing to families.

Thanks for those who responded to my questions in the last Newsletter. It would be really helpful to get some more responses so I am asking much the same question again this month. If you are able to put pen to paper or email me with an answer to the following it would be greatly appreciated:

### **Who would you expect hospital staff to notify about your child's death?**

- Local Doctor
- Maternal and Child Health Nurse
- Illness/Disability related recreational and support groups that you are members of such as such as Canteen, HeartKids, Challenge, Very Special Kids?

Thank-you for your feedback and ideas which are being used to guide us in improving the support and care we offer to families as they grieve.

With Warm Regards



**Maree O'Toole**  
**Bereavement Services Coordinator**  
**Royal Children's Hospital**  
**maree.otoole@rch.org.au**

# *Straight from the Heart*

*Thank you to Yvonne, Alex and Michael. Yvonne has written this poem for her child Alyssa on the 1<sup>st</sup> anniversary since her death. Alyssa died of a brain tumour when she was 3 1/2 years old.*

## **A Year On, and Another Christmas**

Just thinking 'bout an Angel of mine  
You are in our minds all of the time  
Day in and day out, without any doubt,  
Our memories of you are divine.

A lot of the time we are sad  
Thinking of all the hard times that you had  
But we can also be happy, even when times are crappy  
Because we had you, and for that we are glad.

One year has now passed since that day  
December 13<sup>th</sup>, when you went away  
Laying there in our arms, we tried to keep you from harm  
But to Heaven you went on your way.

We miss you our darling sweetheart  
Why did death have to tear us apart?  
We awaken each day, and realise straight away  
The sadness that burdens our heart.



We miss:  
your little secrets, so terribly,  
your running cuddles  
jumping up on our knee  
sharing Tic Tocs & chips  
having “mmmaa” kisses from your lips  
listening to you giggle, so happily.

Christmas is again almost here  
With people all around full of cheer  
We will light up your tree, & remember your face full of glee  
Knowing your spirit is with us so near.

Give “Undies” a hug for us too  
Bet you love having your cat there with you  
Suppose he’s purring all day, chasing butterflies at play  
And loving being with Axel and you.

We love you Alyssa, it’s true  
We send all of our love up to you  
We hope Christmas this year, sees you happy with no fear,  
Playing with Angels as we’re sure that you do.

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  
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Flemington Road  
PARKVILLE VIC 3052



Our mailbox is nearly empty!

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

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

Our guest for the evening will be Ms. Judy Rassaby. Judy has a background in psychology and family therapy and works as an adolescent co-ordinator with bereaved families at Very Special Kids. Judy will offer some creative activities to explore the topic:

**“Bereavement: A Family Journey”**

The newsletter is a team effort. Thank you to the parents of the Parents' Bereavement Support Group, Carol, Jane Miller (Chief Social Worker), Carly, Aleisha and Elisha for their enormous assistance with the creation of the newsletters and to the Social Work Department for its ongoing support.



**Maree O'Toole**  
**Author & Editor**