

# PARENTS' BEREAVEMENT SUPPORT GROUP



Social Work Department  
Royal Children's Hospital

FEBRUARY 2005 NEWSLETTER

*A very warm welcome to the Family Bereavement Support Programme for 2005. We hope that as the year unfolds through the newsletters and groups you will find connection with others, support, information and understanding to help sustain you as you grieve for your child.*

“Being Together: Exploring the Impact of Grief on Parents”.

We welcomed all parents who came together for the first monthly group of the year. In welcoming the parents, we acknowledged their children whose lifetimes had such a profound impact on them and had brought them to this time and place. Coming to a group for parents who are bereaved, we noted reflects (however shaky it may feel) hope, fortitude and commitment to find ways of continuing to live with such an incredible loss. As this was the first group for the year and at least half of tonight's group members were coming for the first time, we spent a little time talking about the group. *The group* recognizes that grief is a unique, powerful and personal experience. However while there may be very important individual differences, there is also a significant common bond between parents who are grieving for their child. Grief is often an isolating, lonely journey. Being with other bereaved parents, and sharing experiences can be very supportive. Receiving and discussing information about grief can help parents as they adjust to the aftermath of their child's death. The group brings these elements together. The group then is a safe place where the experience and comments of each member are respected. Participation is through being a part of the group, listening and sharing stories. Parents are encouraged to talk as little or as much as they feel comfortable to. During the

evening, Jane was to explain that she takes notes for the newsletters. Jane also gave Carol's apologies and best wishes to the group. Carol is in Singapore conducting a series of Grief and Loss workshops and lectures for health professionals.

To help explore the theme for the evening and to set a context for the topics which will follow, we were joined tonight by Ms Geraldine Paine. Geraldine has woven together her experiences as a nurse, grief counsellor, family therapist and family support worker and her personal insights over the past thirty years to support and resource adults, young people and children as they grieve. Our programme first met Geraldine when she was working at the Outreach Grief Services. Geraldine has been a friend to this Programme, being our guest on a number of occasions and offering individual counselling through her work at the North Yarra Community Health Centre.

In preparing for tonight's group, Geraldine had planned for an evening which would offer a time for parents to share *something* of their child and to have some information from Geraldine, on what is known and understood about this most complex of human experiences.

## “Being Together”

### Exploring the impact of Grief on Parents

#### Session Outline

- ◇ Welcome and Introduction
- ◇ Our children—naming our child/ren—naming a memory
- ◇ Lost dreams and hopes
- ◇ The Impact of Grief—an overview
- ◇ Sharing of Experiences—small group discussion
- ◇ Helping/supporting each other  
Self care  
Rituals & Journalling
- ◇ Question time—hand outs—resources  
Evaluation

Geraldine Paine 2005

Geraldine began by acknowledging the sense of privilege she held in attending the parents’ group. She spoke of the “raw vulnerability” that parents who are grieving for their child carry and the “courage” it takes to keep going. Sometimes, being in the group may feel like a *two edged sword*. It can seem that this vulnerability of self joins with the suffering of other parents. The conversation at times can be very painful to hear. And yet within this, there are words which speak of survival, resilience and of a particular solidarity with each other.

Geraldine then asked, if parents felt able to, to briefly introduce themselves, name their child and to say something that was unique (special) about themselves. To break the ice, Geraldine introduced herself! When we had moved around the group and the children were named, Geraldine asked for the children’s names to be written on pages. These were placed in the centre of the group. In introducing themselves and their children members of the group spoke about their daughters and sons. They spoke of how they had had died in infancy, in early

childhood and adolescence, from 2 months to 16 years of age. The children’s lives had ended through Sudden Infant Death Syndrome, congenital progressive conditions, acute episodes of illness, disability and road accidents. Parents told each other how they had been living with their grief for varying amounts of time, from several years to just a few months.

Expressing at short notice a unique quality presented somewhat of a challenge to parents in the group! The parents seemed much better at talking about their beloved children than themselves. However with a little gentle prompting, some of the unique qualities or special abilities included “**just waking up**”, “**being crazy more than unique**”, “**painting china**”, “**bike riding**”, “**still being a mum**” (even when your child has died). **being able to “change (career) direction” and an “unknown uniqueness**”. One mother summed up what seemed to be the feeling of the group in this way; “**Just living the experience we’ve all lived, that’s unique**”. Echoed by another parent as “**Living that’s our own goal**”.

After we had spent this time getting to know each other a little more, Geraldine made several observations which formed the foundation of tonight’s conversation. Often parents who are grieving, she said are “caught in the busyness of grief”. They will “adapt their grief into everyday living... but they never get over it”. While, as Geraldine continued “the physical death” means the child so loved, is no longer with the parent, “nothing can erase the child in the memory and in the heart”. “They will always be with you”, Geraldine said “until you are no longer with us”. “After the death of a child” Geraldine observed, “life as it once was known will never be the same”. As Geraldine was to explore during the evening, in our community we have come to understand that the nature of the parent child relationship and the unfolding of grief means that there is ‘never’ a time when parental grief can be completely ‘finished’ or ‘done with’. Although on one hand appealing, maintaining an expectation that grief will somehow be ended may set an unrealistic goal for parents. Geraldine encouraged parents to recognize the continuing relationship that they have with their child. Admittedly Geraldine commented that

this relationship is in a very different form. Geraldine has seen the emotional damage or burden that unrealistic expectations and misinformation can place on those who are grieving. She exhorted parents, if challenged by

those who are not bereaved, that they should be over their child's death, to say "I'm not over it" and then to tell people to "go jump". At this point, a number of nods were observed!

## Grief and Loss

### What is grief?

Grief is a universal response to a loss. Not everyone will grieve in the same way so it is important to allow each person his or her own style, space and time. Grief is a process that takes time and is dependent on many factors including:

- The relationship/friendship you had with the person who has died
- The support/understanding you receive from others—your own network-family, friends and community- (including professionals
- Your own coping style and how you have handled similar situations of loss and grief in the past—your own emotional well being.
- How the person died—circumstances, suddenness etc

### SOME COMMON GRIEF RESPONSES

◇ shock, disbelief, despair	◇ loss of control
◇ numbness	◇ dreams/flashbacks
◇ memory loss	◇ yearning
◇ sense of helplessness	◇ confusion
◇ repetition	◇ social withdrawal
◇ anger/fear	◇ sighing
◇ anxiety/sadness	◇ feelings of abandonment
◇ tearfulness— crying/ sobbing	◇ isolation
◇ sleeping difficulties	◇ weight loss/gain
◇ guilt blame	

No two people will experience grief in the same way—some people experience a combination of some of the above grief responses at the same time whilst others may just feel sad. There is NO right or wrong way to grieve.

### THINGS THAT HELP

- \*Talking— sharing your feelings, experiences and memories with someone you trust and who is understanding
- \*Exercise— walking, swimming etc
- \*Sleep—ensure you get enough sleep and rest
- \*Diet—eating small amounts of nutritious food
- \*Journaling—writing down your feeling and memories
- \*Rituals—remembering and celebrating the persons life

In continuing to explore the experience of grief, Geraldine spoke about how during pregnancy parents often “dream our child’s life away...we want our kids to grow up and to be the best”. A father with his tongue a little against his cheek **“no child is as beautiful as ours, ...no child is as perfect”**. Suddenly, however with the child’s death the dreams “are severed and cut short”. **“You’re never prepared for it”** were the words of one parent. Expressed by another parent **“It feels like I won’t finish the job I started”**. One group member reflected that some of her dreams that had been lost would be **“invisible”** to other people. **“It’s not just the rolling over, the walking and getting teeth...my daughter won’t ever be an aunt for the others”**.

Those who understand or who will stay around may be *invisible too*. From her time supporting bereaved parents, Geraldine has seen how “true friends are with us in hard times”. Yet frequently grief will define who is a friend and who isn’t. There can be “fair weather friends” who Geraldine suggested, will not be there when they are most needed. **“I hate having to initiate the contact...I’ve had a terrible day... how can I be fine?”** was the response of one member of the group when we thought about the role friends can play in supporting grieving parents. Earlier in the evening the comment to a friend of a member of tonight’s group was how being a supporter of a bereaved person is regarded by parents as a unique and very important quality. Many times as Geraldine mentioned there will be “surprises amongst the friendship circle”. To illustrate Geraldine explained that typically when you have your 21<sup>st</sup> birthday party, you might have a hundred people at the party. Then when you turn 40 perhaps there could be about 50 or 60 guests. By the time you get to 50 the list is short and it’s likely that those at the party may be more acquaintances than friends. This process coupled with the impact of grief will reduce the number of friends who can be counted on. Recent decades, as Geraldine noted, have brought many changes to our knowledge about the nature of grief. In her professional life, Geraldine has witnessed many changes in the care offered to parents who have had a child die. Thirty years ago, Geraldine remarked, if parents had a child who died, they were not able to hold or spend time with their child after death has occurred. Now as several parents within the group

had experienced there is usually a time to be with the child and to gather up precious mementoes of their life. These may be photographs, locks of hair and footprints. These treasured objects Geraldine described as being means to help capture and support memory. Memory, Geraldine emphasized throughout the group, is one form of connection or feeling of closeness with the child. These feelings often defend against the pain of grief. Yet those around mostly *don’t allow* bereaved parents to share their memories. They may feel uncomfortable. However sharing a memory can help to preserve it and protect it against the dangers of time. In particular Geraldine has found that often there is no space to talk about the experiences of pregnancy or of the child’s early days. And yet parents love to talk about these times.

In revisiting memories, members of the group recounted with delight some very precious moments. We heard of **“The one day when everything was alright when it was filled with unbridled possibility”** and **“whispered conversations”**. We laughed at the tale of **“the wry smile... that was just hilarious”** **“wedding ceremonies in the backyard... being so cute”** and *of walking wees and sleepy words*. We shared in the recollection of a pregnancy that was **“an unexpected beautiful surprise”**. Group members met the baby daughter who after two boys were surrounded by **“a sea of pink”**. Wonderful stories of children were told by their parents. Stories of children who had in some ways been *written off* (because of the severity of their disability) by health professionals and yet came to be so loved and loving in their family. *We met* the son whose **“basinet was plonked in the centre of the action...(and) learned how to smile”** through the time and care he enjoyed with his family. Some of the quirky times were recalled also by parents. Times of eating lollies at 3am, once unthinkable but when your child is dying, **“You do it ... You’d do everything you want, you do anything to put a smile on their face, you know your child, you’re only trying”**. Members of this group know first and foremost what quality of life really means. All these memories and a thousand private ones were savoured.

Geraldine remarked that “other people and relatives hold different memories (of your child)

they are to be enjoyed but they are ...not your precious memories". Again Geraldine explained that it was helpful "to keep talking and sharing, important to keep the connection with the person who is no longer physically there". For as Geraldine said once more the connections between parents and their child "never ends". Even when the child is no longer physically there, there can be a way of reconnecting through memory and meaning. From sharing these memories, we thought of those unexpected moments that bring parents unstuck. A mother recounted her recent experience. **"I balled my eyes out to someone I don't even know at Centrelink, I think I should be able to control this"**. Geraldine was quick to point out that there are "no rights or wrong" in grieving. "You are only human...it is how it is." A trip to Centrelink can be loaded with memory, connotations and stress. It is yet another time which emphasizes the loss parents live with. This time the loss may be symbolized by not being regarded by the Government as a parent or carer. Sometimes, it was thought there can be a sense of not wanting to cry to protect others. When you *end up* crying you feel somehow you've let someone else down. How complex is that?

As we spoke more about experiences and memory, it was acknowledged that often memory brings with it tears. **"I cry myself to sleep"**. "Tears are healing... they are okay" Geraldine responded. In describing the therapeutic value of tears, Geraldine explained that when someone cuts their finger, these tears they cry out in that sort of pain, are a mixture of saline (salt) and water. But the tears of grief contain endomorphine. This is a form of natural painkiller. Endomorphine has a numbing pain effect. This as Geraldine noted this is how the expression have a "good cry" comes about. Consequently, crying she said "is a natural release and is appropriate for both men and women". Those who are "more private" in their character Geraldine suggested may find they need to create a particular space where they can sob their hearts out. The shower was named as a possible place!!

Within the many powerful emotions that grief can evoke, Geraldine continued, there is also anger. When we are children, Geraldine has seen, we grow up with the message that frustration and

anger are bad. "Anger is a fabulous emotion if it's used appropriately" Geraldine ventured. Anger can create a change in the self and surroundings. Anger needs to be harnessed. The risk of not expressing anger, Geraldine believes is that it may manifest itself in physical ways. For example the tightness in the chest or the feeling of nausea in the stomach. Releasing anger in a safe way, perhaps punching pillows, screaming (let people know first), or ripping tissues out of tissue boxes can be useful. Geraldine's observation to the group was "You have a lot to be angry about".

Over time as they grieve and express their emotions - parents, Geraldine has seen will "discover what is unique within you that connects you with your child... you'll know". Geraldine described how these connections will often be very private. Sometimes, as has been discussed in other groups on other nights, a private way of expressing grief may be wrongly assumed by others to be not grieving. From her times with talking with men who are bereaved Geraldine heard how commonly men will have their own particular time and way to express grief. This may mean taking themselves away from the view of others to physically release their emotions. Geraldine has known fathers who in the morning say hello to (photos of) their children. At day's end they tell them how their day has gone. In the group a father spoke about the beautifully framed photographs he has of his son and wife which he takes on his business trips and which adorn his hotel rooms. There are photographs too at work. He shared how he hopes that a cleaner when dusting will pick the photograph up, look at his son and think **"what a beautiful boy, that's a buzz"**.

In thinking further about the impact of grief and how it can become invisible, Geraldine encouraged parents who still had living children not to "leave them out of the picture". Usually she said a child's *position* in a family will change with the death of a sibling. For example the younger child becomes the older sibling or becomes the 'only' child. In death the sibling may become larger than life and take on heroic characteristics. This may leave the living child feeling resentful or forgotten. As one mother said her surviving child had challenged her about **"what about having time for me now"**. It may



be supportive for families who are grieving to include their living children in the rituals of grieving. Honesty and communication were also encouraged by Geraldine within families. To illustrate, Geraldine said a partner may open up communication with their spouse by beginning “what I’m going to say is difficult but I need to talk about...”

Naming and owning feelings is a challenging process. Yet they seem so critical in avoiding confusion and misunderstanding. Simply asking *how it is going* for a family member can open up a conversation. Communicating, Geraldine explained, when there are feelings of shock and confusion can be very difficult. To illustrate Geraldine used the time of diagnosis as a time when through shock and stress only so much information can be taken in. It may be then that following the death of their child parents want and need to pursue information.

For many reasons, families may have unanswered questions about the child who died or hold fears for living children. These are fears they need to talk over. “Your worries come out of lived experience”, Geraldine said. “When you lose a child there is a fear of who is next”. Several parents had found that “others will stick in their tuppence worth...they make you feel guilty...did I play a part in it (my child’s death), it sticks in your mind... you do look for a reason...” you ask yourself ‘why’ a billion, million times”. Geraldine has seen there is often no real answer to *Why*. “You won’t have the answer but you learn to live with the gap in the jigsaw”.

Amidst times when there is a feeling of having no control Geraldine considers that “people’s insensitive comments can contribute to feelings of helplessness and guilt”. **“You are meant to protect your child... it’s our job”, rejoined one parent.**

In this context of seeking information, we talked about how some families find it useful to access the medical record through the Freedom of Information processes (FOI 1982). A child’s medical record is a part of a child’s story. Reviewing the UR for one couple had been “a

**breath of fresh air...we were reassured everything that was done, was done right and all that could be done, was done”.** It was very significant for the family that they knew about **“those last hours...we knew everything else”.** One family were using a copy of their child’s UR for the scrapbooking of their child’s life which they had been doing. They found there were **“a few things we didn’t know”.** A child’s medical history can help, too, with maintaining the memory. The memory held in a history that may be bittersweet. As we spoke about important conversations with doctors following the death of a child one mother said how she felt **“guilty (that she was) taking the doctor’s time from other children”.** A number of families suggested what they had found to be effective and efficient methods of contact with doctors. These included emails or letters. Supporting bereaved families it was agreed, is a significant part of a doctor’s role. Their concern and service does not end with a child’s death. Of course, like most areas of life there will be those who do this with more sensitivity and skill than others. The sense of the group was hospital visits after a child’s death are very meaningful. From her experience, one parent said **“I would recommend that these appointments are not left to families to follow up.... the hospital should have some way of organizing them”.** Appointments should be in Geraldine’s view “when you’re ready”. There is no neat time line for them. More than one may be needed.

At about this point in our conversation, we had a brief *to’ing and fro’ing* about the costs associated with the Freedom of Information process. Several families had incurred costs with their requests. We undertook to clarify this. It seems that under the Act, application and copying prescribed fees can be charged. Application fees can be waived for holders of Health Care Card or Pension Cards. However application fees can also be waived on compassionate grounds. In some situations photocopying charges can likewise be reduced or waived on compassionate grounds.

Out of the image the mother had painted earlier of being so overwhelmed, tearful and miserable at Centrelink, Geraldine spent a few moments talking about the concept of regression in grief. In acute grief, Geraldine explained, there is a

concept that some adults may regress to about the developmental stage of an 8 year old. They are not functioning at their adult best. In their regressed state people who are grieving are seeking a time when they will be comforted and looked after. In these times their behaviours may become almost “robotic or automatic”. It will be hard to remember, Geraldine remarked that “you’ve actually done things. For example you’ll check that the door is locked about a zillion times”. Geraldine also spent some time talking about some of Freud’s work on grief. In particular that the experience of loss and separation start very early in life, from the time we leave our mother’s womb.

Grief, Geraldine noted, brings such a powerful impact, that the body and mind need to be cared for. Time out, diet, exercise and sleep are essential. Geraldine also explained how in dreams there are often thoughts, feelings, images that are too difficult to be thought of consciously. Thus dreams and dreaming are also beneficial. They are part of the work of grief. During the evening Geraldine told parents about a meditative exercise they can try out for some respite and replenishment.

Animal companions for adults and children were also mentioned by group members a source of comfort, fun and distraction. (However never as replacements for the one who had died).

In living with loss, Geraldine said that it is important to be able to “laugh and live again” (you can grieve and remember...) you’re not putting life on hold forever”. Many people known to Geraldine who had experienced the death of someone they love, have been able once more to see meaning and purpose in their life.

While we continued to explore what can be beneficial to support the ‘grieving self’, Geraldine spoke about writing. Many bereaved people whom Geraldine has worked with have found writing or journalling supportive to them. Writing can free up the thoughts that go round and round in the head. Putting them down on paper can place some distance between them. A parent remarked “**I write down screeds and screeds**”. Yet others in tonight’s group had experienced a writer’s block! Some people, Geraldine recalled, have used one word to

reflect or meditate on for a while and then move into writing.

Next Geraldine talked with parents about more formal supports or resources they could draw on as they grieve. Counselling may be a valuable support. However “counselling is not for everyone... nor are support groups” observed Geraldine. Geraldine suggested that parents can “shop” for the counsellors that they can relate to and feel comfortable with. The counselor must be their choice. Once more, the comments made earlier in the evening about the impact of being in a group echoed. The mutual and shared pain of being in a support group may unintentionally add to the load carried by a bereaved parent. This may need to be addressed.

Towards the end of the evening we realized once again that there was so much more to be said. Indeed Geraldine had prepared so much material that we did not explore on the night. We wanted to do justice to this highly relevant material but also to be respectful to parents’ stories. Geraldine very generously offered to come again to another group later in the year.

To conclude for now then, Geraldine said after a child has died, “life has changed into a new life.... If you could avoid your grief you would, but avoiding grief would mean denying the child”. And that is something this group of parents would never do. So we ended this group as we had begun by recognizing the bond between parents.

We are deeply grateful to Geraldine for the time and care she took with her presentation and the thoughtfulness and respect she showed parents. We are looking forward to her returning to the group later in the year. As we moved towards more informal conversation over supper, Jane suggested to parents that they take care with their feelings and thoughts that may emerge from being part of the group. Talking with a trusted friend relative or making a private time with Jane or Carol were suggested as ways of attending to anything that unexpectedly arises or needs to be followed through.



## BOOK RESOURCES FOR FAMILIES

### Death of a child

Dear Parents	<i>Joy Johnson</i>
Empty Arms	<i>Sherokee Iise</i>
Children Die Too	<i>Joy and Mary Johnson</i>
A Broken Heart Still Beats	<i>Anne McCracken &amp; Mary Semel</i>
Strong & Tender (acknowledging father's grief)	<i>Pat Schwiebert</i>
Little Footprints	<i>Dorothy Ferguson</i>

### Death of Sibling

A Birthday Present for Daniel	<i>Juliet Rothman</i>
We Were Gonna Have a Baby, But We Had An Angel Instead	<i>Pat Schwiebert</i>
Stacy Had a Little Sister	<i>Judith Friedman</i>
The Empty Place	<i>Roberta Temes</i>

### Other Titles

When Dinosaurs Die	<i>L.Kramsny-Brown &amp; M Brown</i>
Badger's Parting Gifts	<i>Susan Varley</i>
Coping with Grief and Loss	<i>Mal McKissock</i>



Geraldine Paine 2005

# *Straight from the Heart*

*Our sincere thanks to Mrs Angela Bathman, Mitchell's mother for sending us her poem 'An Act of Love'. An Act of Love records exquisitely the many dimensions of love, grief, and memory coloured by excruciating decisions and conflicting feelings. Through Angela's words we hear once more how the experience of a child's death reveals the essence of life. We feel other families who grieve will understand the experiences within Angela's piece of writing.*

*An Act of Love is printed in honour of Mitchell Leigh Bathman.  
23.9.2004- 28.9.2004*

## *An Act of Love*

An act of love is what they called it.  
To let our baby go.  
But heartbreaking is the reality that  
We will never see him grow.  
Our grief is still so fresh and raw,  
Our pain for all to see,  
But we know why Mitchell came into our lives  
For everyone to see

Do not take for granted  
Your children, family or friends,  
The little things in life are nothing,  
What matters is your heart.  
So take time to appreciate  
What you have around you,  
Don't let it fall apart.

Nothing lasts forever,  
Just ask us, as we know.  
But Mitchell grew his wings and flew  
For he could stay no more.  
We love him now and always will  
Our beautiful baby boy,  
He taught us what is important...  
LIVING, LOVING, CARING, SHARING.

Never forgotten, always remembered  
Forever loved.

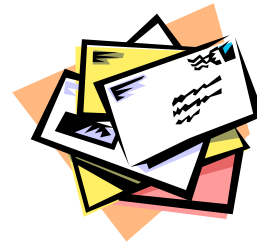
In loving memory of Mitchell Leigh Bathman



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  
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Our mailbox is nearly empty!

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

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

**“Putting One Foot In Front of the Other: Surviving the Unthinkable”.**

Our guests for the evening will be Ms Mary Hanson and Ms Bette Phillips (National Association for Loss and Grief). Mary and Bette, who themselves are bereaved parents and community parent supporters will explore possible ways of expressing and living with grief.

Thank you to **Geraldine**, the parents of the Parents' Bereavement Support Group, Carol, the Chief Social Worker, Jane (Miller), Jodi, Rebecca and the Volunteers Department for their enormous assistance with the creation of the newsletters and to the Social Work Department for its ongoing support.



**Jane Sullivan**  
Author & Editor