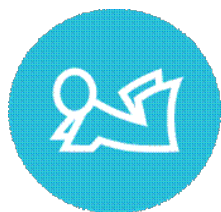


FAMILY BEREAVEMENT SUPPORT PROGRAMME



Social Work Department
Royal Children's Hospital

NEWSLETTER MAY 2009

Welcome to the May 2009 edition of the Royal Children's Hospital Family Bereavement Support Group Newsletter. The purpose of this Newsletter is to provide those of you who are unable to attend the Parents' Bereavement Support Evening Group with a written summary of what was discussed in the monthly Group. It is hoped that by reading the Newsletter you will be provided with a link with other bereaved parents and family members, and that you feel you are not alone in your grief.

'Being' a Bereaved Parent

The invited guest presenters for the May meeting of the Group were Judy Dowling and Ray Stowe from The Compassionate Friends (a self help organization for bereaved parents). Both Judy and Ray have experienced the death of one of their children. They introduced the evening's discussion by speaking from their own experiences about the many and varied aspects of life as a bereaved parent.

Those present were then invited to speak about their children and about how they were thinking and feeling at the moment.

Expressions of love and loss

The grief, sense of loss and expressions of love parents have for their children was immediately spoken about by those in the Group: **"I'm struggling at the moment"**; and **"every day is hard"**.

They spoke about yearning for the physical presence of their child. **"I would give anything to have an extra minute with him"**. One

mother said: **"I miss (his) need for constant attention. I never thought I would, but I do"**. And another mother explained: **"I can look at his photo forever, and look at every little crease on his face ... his teeth marks on the spoons in the drawer mean so much to me"**.

One mother expressed the confusion and frustration many parents experience. **"I don't know how to 'be' anymore. I don't know who I am anymore. I'm still finding my way"**, and **"(I'm) sick of everything ... sick of people feeling sorry for me or not feeling sorry for me ... sick of people judging me ... saying 'you should be...'"**

The need to protect

Bereaved parents often feel that they have failed to protect their child and guilt and self-blame are common reactions. As one parent said: **"I blame myself for my son's death ... I was driving ... I was his mother ... and I was supposed to be looking after him"**. Another parent explained: **"(My son) had many sei-**

zures over his lifetime. I was with him all the time. I used to always sleep outside his room ... but I didn't hear him that night".

A mother spoke about having to make the decision to turn off life support - probably one of the hardest decisions anyone ever has to make. As she said: **"I think about the decisions we have to make as parents and the impact of those decisions on our role as parents"**. For this parent, the guilt associated with her child's death influenced her decision about whether or not to have another child. **"I felt I didn't deserve another child. I was his mother and was supposed to be looking after him ... and he died"**.

Being at the 'place' where the child died

Coming to this Group, (which is held in the Royal Children's Hospital), can be a difficult journey for some parents. **"It's hard to come back to the Hospital as (my son) died here"**. For others, coming to the Hospital can mean some respite from the place where their child died: **"My son died at home. Now I want to bulldoze my home ... I need to get out of the house"**.

Acknowledging the children who have died, and their legacy

Parents in the Group all agreed that they needed to acknowledge their child who had died. All spoke with pride about their children. As one father said: **"It's incredibly important to me that I acknowledge (my son)"**. A mother explained: **"I think each of our children came**

here to teach us something. (My son) saved my life. I was in a 'dark place' in my life before he was born. He saved my



life. I am so glad he was in my life".

Passage of time

Parents spoke about the meaning attached to the passage of time since their child's death. One father said: **" ... coming up to the anniversary ... but it's like an anniversary every day"**. A mother explained: **"In July (my daughter) will have been dead longer than she was alive. I'm scared of losing touch with her"**. Many bereaved people share these fears, as the time since their loved one's death extends. Later this mother explained: **"It's inevitable that I don't remember everything about her and her life. I write my memories down so I don't forget. I want to grieve ... I'm scared I'll forget"**.

Dealing with other people's comments

The discussion turned briefly to situations where other people had not understood the depth of grief experienced by bereaved parents. Death is a difficult subject and some people do not know how to respond to a person who is grieving. Some people, although they don't mean it, say and do all the wrong things. As one parent said: **"I realize now that I can't expect other people to know how I'm feeling"**. A father explained: **"I found that all my expectations (about support provided by other people) were blown away"**.

Other children in the family

While they can't take away the pain of the loss of one of their siblings, the comfort provided to parents by their other young children was spoken of lovingly during the Group. As one mother said: **"Before (my subsequent child) came along I couldn't get out of bed in the mornings. He hasn't replaced (my other son), but he is a reason to get out of bed in the morning"**. Another mother explained: **"I get up for my boys ... (my son who died) was one of three. He is always missing. I still think in 'three's' ... I'm still doing things in 'three's' ... I still do things for him, but he's**

not here.”

When the child who died is the only child

When an only child dies, parents often feel that they have lost their identity as a family. As one mother said: **“(Our son) was our only child. (My husband) and I have to become ‘two’ again, instead of ‘three’”**. She went on to say that being an only child meant that she could devote all of her time to him. **“I’m grateful that I could focus entirely on him ... I could spend as much time as I possibly could with him in the Hospital, because I didn’t have to worry about (my) other kids.”**

Having another child

The decision to have another child is a very personal one. For some couples, having another baby is not possible, or in some cases, the decision to have another baby is a very complex and complicated one. As one parent in the Group stated: **“Being a mother – that’s my purpose in life. I would love to have another baby but we need to be sure that our next baby is not born with a genetic condition. We need to make informed decisions”**.

The ongoing relationship with the child who has died

The enduring, special and loving relationship parents maintain with their child was again evident in this Group. This bond parents have with their child was summed up in the following ways: **“They are still a part of you”**; **“They are in your heart”**; and, **“He’s always in my heart”**. As one mother said: **“(My son) is still with me. He chats with me constantly. I ‘know’ he’s there”**.

The impact of a child’s death on other family members

A paternal grandfather, who attended this Group for the first time with his son, spoke movingly about his beloved granddaughter, who was almost 7 years old when she died sixteen months ago, and had cerebral palsy. He said: **“It is get-**

ting harder for me ... I was closer to (her) than even my own children. Since (she) died, my 84 year old father and a lifelong mate of mine died at the



age of 70. But I’m finding it much harder to handle (her) death ... It’s such a bloody terrible thing. I don’t say ‘why?’... we were lucky to have her for seven years. And she was lucky to have (her father / my son). I think about her all the time. She loved to laugh ... loved to be happy. Her last Christmas, (my son) walked in with her and she lit the place up ... that’s what she did ... she always lit the place up”.

What helps?

The group discussion also focused on what bereaved parents feel is helpful to them. Some of this Group’s ideas included:

“Having someone to grieve with you helps”.

“My wife and I have been blessed with wonderful friends. It’s important to find out who your friends are, the really solid ones, and stay with them”.

“I choose to be around people who support me. Some of them are people I work with”.

“We make sure (our son) is part of every occasion and we stay in contact with people who knew him”.

“Music dissolves me, but it helps me too”.

“Spending quiet time on my own helps – you know the notion of men going into their sheds”.

The value of being in contact with other people who have had a similar experience

The parents who were present in the Group then spoke about the understanding, acceptance and support they had received when attending groups for bereaved parents.

“Outside I often feel lost, as if I don’t belong. But here, what I often think is what other people here in this room think. It helps me feel less alone”.

“I can’t express what it means to come here to this group ... there is a compassion in this group ... I don’t get it from other people”.

“SIDS and Kids and this group at the RCH have been helpful. You know you are accepted and understood by the people here”.

“That’s why I come here, because I know people here understand”.

Changes over time

Ray, one of our presenters from The Compassionate Friends, concluded by saying: ***“It does get easier. But it takes time. It’s six years down the track for us now, and I have to say that I have come out the other end. But, I do have to stand still some days. I will always have memories of my son, and no-one can take them away from me. He will always be my son”.***

The grandfather, who had spoken earlier, provided a memorable statement for the parents to consider over coming days and weeks. ***“Your loved ones, including your children, must be so proud of you ... it’s been a privilege to be with you.”***

Closing

Judy and Ray were thanked for their honest, insightful and meaningful contribution to the Group’s discussion. Everyone then came

together over coffee, and continued to share stories of their children, their lives in general and ... a few laughs.

The Compassionate Friends is a self help state-wide service and offers:

Bereaved Parent Support Centre

24 hour phone support

Freecall number 1800 641 091

Support groups are held in suburban and country areas and include groups for older siblings

Bi-monthly Magazine

Extensive literature on parental and sibling grief – mostly written by bereaved parents and siblings

A library

The Compassionate Friends is soon to move to new premises at 173 Canterbury Road,

Canterbury 3126

PO Box 171 Canterbury 3126

Phone (03) 9888 4944

www.compassionatefriendsvictoria.org.au

Vivienne Bateman

Social Work Department

Royal Children’s Hospital



Straight from the Heart

Grandparent's Grief

A Unique Experience

The Grief Of A Grandparent

- ⊗ The death of child is a devastating experience for a family. The grief that flows from this may affect family members in various ways.
- ⊗ The grief that grandparents experience is unique. They grieve for their grandchild and also grieve for their adult child who is hurting.
- ⊗ Grandparents often share a special bond with their grandchild. They may experience the loss of their dreams and hopes for their grandchild's future. There may be a sense of what should have been and now will not be.
- ⊗ When a grandchild dies, grandparents may feel a range of emotions and like other members of their family, they hurt and suffer. They too need understanding and information.
- ⊗ Grief may involve a range of emotions such as sadness, regret or anger. Often grandparents struggle with feelings of guilt. It is never expected that a grandparent will live longer than a grandchild. Grandparents may ask "Why not me?"
- ⊗ Grandparents may also encounter a variety of changes relating to their stage of life such as retirement, ill health, and death of friends and family. This could add to the impact of the grief which is felt when a grandchild dies.

"There is a different bond with that child that only grandparents and the grandchild understand."

Looking After Yourself

- ⊗ Grief affects the whole person; the emotional, spiritual, social and physical self.
- ⊗ Allow yourself time and space to grieve.
- ⊗ Talk with people who are supportive and will listen to you without judgement. This may be a friend, family member or someone from your local community.
- ⊗ Allow yourself to laugh and remember the good times with your grandchild.
- ⊗ Find a safe way to express your feelings, both positive and negative.
- ⊗ Do something nurturing for yourself; read a book, watch a film, spend time in the garden or go for a walk.
- ⊗ Be mindful of your health. Consult your General Practitioner.
- ⊗ Create a positive memorial for your grandchild such as planting a tree, creating a special garden or even establish a fund in your grandchild's name.
- ⊗ Many people who are bereaved find assistance and support from professionals within their community such as their GP, social worker or a leader or member of their faith community.

The Social Work Department at the Royal Children's Hospital, your GP, local council or Community Health Centre can put you in touch with an appropriate support service.

"It helps to know we are not alone."

Ways You Can Support Your Adult Child

As a parent you may experience feelings of helplessness and frustration as you watch your adult child suffer and are unable to take away their pain. Below are some practical suggestions that other bereaved grandparents have found useful. These may assist you to support your adult child through their grieving process.

- ⊗ Listen to your child and respect the way they manage their grief.
- ⊗ Take cues from them on how they would like to be supported.
- ⊗ Acknowledge that grief can strain even the closest of relationships.
- ⊗ Accept that you can not take your child's pain away. However you can be a source of comfort, support and practical assistance.
- ⊗ Encourage your child to talk as much and as often as they wish.
- ⊗ Show them that their child will not be forgotten, display photos, acknowledge anniversaries and share stories.
- ⊗ If there are other children within the family, supporting them in their grief will also assist your adult child, as they may be unable to do so. Offer to look after them if that would help their parents.
- ⊗ Offer practical help such as cooking, answering the phone or letting people know what has happened.

"We feel it for our children and our grandchild.... tears flow for them both."

Suggestions About What Bereaved Grandparents Have Found Helpful

- ⊗ Realise that you are not alone; share your experiences with others that grieve.
- ⊗ Create a special place or activity where friends and family can remember your grandchild.
- ⊗ Seek comfort in your philosophical, spiritual and religious beliefs.
- ⊗ Read about grief, loss and life changes.
- ⊗ Have a 'good cry'.
- ⊗ Spend time with other grandchildren.
- ⊗ Be open and honest with your children - don't try and hold back your tears.
- ⊗ Spend time in nature.
- ⊗ Express your grief creatively through activities such as gardening, quilting, writing, painting, scrap booking, creating a photograph album of your grandchild or perhaps even doing activities your grandchild enjoyed or that you did with your grandchild.
- ⊗ Take one day at a time.

Contributions such as responses and reflections on the groups' themes, poems, letters, songs, quotations from parents, grandparents, brothers and sisters and friends are most welcome in the Newsletters. Share your thoughts, experiences and questions with others who are bereaved.

Please forward them to:

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



Our letter box is waiting!

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

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

Thursday 18th June

7:30 pm – 9:30 pm

Seminar Room 2, 4th Floor

Front Entry Building

Royal Children's Hospital

We will not have a guest presenter at the June Group. We will have a discussion about "To Share or Not to Share: the inside and outside face of our grief".

Please join us in June

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



*Vivienne Bateman
Editor*