



# FAMILY BEREAVEMENT SUPPORT SERVICES

Social Work Department  
Royal Children's Hospital

## NEWSLETTER OCTOBER 2009

Welcome to the Royal Children's Hospital's Family Bereavement Support Services' October Newsletter. This month's Newsletter includes a request for your feedback about the Family Bereavement Support Groups and the RCH Memorial Service, a summary of group notes taken during the October Group evening, without participant names, as well as quotes from handouts used from the evening's topic, "The Grief of Grandparents". This month's "Straight from the Heart" was used during the evening for reflection and discussion.

We hope that as you read the Newsletter that you will find comfort, support, reassurance, connection and hope for the future.

## *The Grief of Grandparents*

### **Wanted: Your Feedback!**

As we are coming to the end of the year, we are seeking your input on planning for the Family Bereavement Support Groups for 2010. We are also wanting feedback about your experience of the RCH Annual Memorial Service. Evaluations were sent out a few weeks ago to people who attended the service this year and we would appreciate your responses to help us with future planning. Thank you to those who have already responded.

Currently all of our Family Bereavement Support Groups occur on a Thursday. The quarterly day time groups happen from 10 am – 12 pm. The evening groups both for the newly bereaved and bereaved families run from 7.30 pm – 9.30 pm. We have had some feedback recently that the evening group finishes a bit late for some families and that the Thursday evening doesn't suit everyone.

We would appreciate your ideas about both days and times as well as the topics you would like or have found useful in the past and think others would benefit from as well. We are asking that families email, write or phone us with helpful thoughts and suggestions.

Please email [karen.ditty@rch.org.au](mailto:karen.ditty@rch.org.au), ring on 9345 611, or mail your ideas in to The Editor at the address on the back page of the newsletter. Your ideas are greatly appreciated.

### **The Grief of Grandparents**

Our October evening bereavement support group was lead by Denise Same, a bereavement counsellor and group facilitator of a grandparent support group with SIDS & Kids. Denise brought along a co-guest speaker for us, Marilyn, a grandparent supporter also from SIDS & Kids.

The aim of the group was two-fold. Firstly to look at grandparents' grief, talking about what can be helpful both for their children as well as themselves. The second part was focused on what bereaved parents need/want from their parents, again focusing on what is helpful and not.

The key aim of the evening's discussion was to highlight that *"when a baby or child dies, it has an impact on the whole family... There is often a lot of attention on the grieving parents, who are the primary grievers, and how grandparents may find themselves forgotten at times."* Denise highlighted that *"the grief of grandparents can be as intense and painful as the grief of parents."*

The death of an infant or child is *"an upside-down order of things where grandparents can experience a triple grief: the loss of the grandchild, the loss of their adult child as they knew them, and their own loss of identity and ability as a parent to help their adult child."*

Denise spoke of how frustrating it can be for

grandparents, who want but can't make it better again. A key reason for this is that grandparents witness the pain and suffering of their own child and are helpless to fix it or make it go away. The grieving adult child is now someone different and often the grandparent doesn't know what to do or say.

In her work as a grief counsellor, Denise shared her observations that *"the death of a beloved grandchild is one of the hardest things a grandparent ever has to face. All of their hopes and dreams for the future are shattered as the whole family is faced with an unbearable tragedy."* She highlighted that *"grandparents expect that they will die before their children and certainly before their grandchildren."*

Because of this impact, Denise asked Marilyn to share her story with the group and Marilyn confirmed Denise's experiences of



helping bereaved grandparents and families.

### A Grandmother's Story

Marilyn told her story of the death of her twin grandchild, conceived by IVF, but who died at 36 weeks gestation. She remembered how she had been at the ultrasounds and been an active support during the pregnancy and then of the devastation of the birth of only one live baby. Marilyn spoke of the simultaneous experience of grieving the death of one child while celebrating the birth of another and how the mixed emotions were overwhelming and confusing. She spoke of how with the whole family in acute grief that she felt ***"I couldn't do anything. I felt useless and helpless. My daughter didn't want comfort from me and couldn't say what she wanted or needed. My heart was breaking because I couldn't do anything. I'd go home and I'd cry. I couldn't stop her crying and I was crying. I realised I needed support too. I was lost. I was going in a daze, then I was connected to Denise's group and we all shared that the hardest part was not being able to help our children and feeling useless."***



Although there were no bereaved grandparents at our evening group, many parents reported finding the discussion both interesting and useful. One parent remarked ***"our experience is that the relationship with his parents was really hard and worsened about 2 months ago. I had shut myself off because they didn't talk about our son. Their focus was on the other grandchildren and I was false around them, wearing a mask. I ignored them and felt ignored by them."***

### Common Experiences & Reactions

Denise highlighted how this was a common experience among bereaved families and grandparents, stating that everyone's background comes to the fore when there's grief. ***"They want to make you better, but they don't know how. They don't know what to say."***

Marilyn recalled how her daughter pushed her away, ***"but she wanted me there. Whatever I did it wasn't right. She was very angry and projected her anger at me and onto me. I think she did this because she knew I wouldn't run away. I haven't ever lost a child and had a living grandchild. I didn't know what to do.... She's changed. Her husband's changed and I find it very sad."***

One of the handouts given out on the night called ***"You Can't Win With Me"*** gave the following advice to grandparents:

***"If you don't know what to say to me, that's OK because I don't know what to say to you either."***

***If you see me smile or laugh, don't assume that I must have forgotten my baby for the moment. I haven't. I can't. I never will."***

***If you see me and think that I look sad or upset, you are probably right. Today might be an anniversary for me or some event might have triggered a wave of grief in me. If you don't say anything, I'll think you don't care about me, but if you do say something, it might make me feel worse. You could try asking if I want to talk, but don't be surprised if I say no."***

***Don't give up on me, please don't give up. I need your caring. I need your attempts, however feeble, however trite you might feel they are. I need your thoughts. I need your prayers. I need your love. I need your persistence."***

Excerpt from SANDS November 1992 newsletter

### Respecting Individuality

Discussion over the course of the evening highlighted that it is very important to respect the individuality of every child, whether a child or an adult. Everyone has different ways of doing things and needs change every minute. The experiences of grief and bereavement are no different. One parent stated ***"my mum and dad are there to provide emotional support. His parents provide practical support. I know I shouldn't and can't expect the same, but it is hard."*** Another agreed ***"that's right. You can't say anything. You don't know what to say yourself. You don't know what you need at the time."*** And still another said, ***"My mother was speechless. She didn't speak much. She was quite shocked herself and didn't know what to say."***

### The Importance of Support

It is important for grandparents to be there and be available for their adult child. Being there doesn't mean that they will get it right, but it is about being a support, someone who can be called on and someone who can ask about their well being, someone who won't disappear just because



the funeral is over.

For some parents in the group support of their own parents wasn't possible. ***"In my case, my sister-in-law was the most helpful. If I asked her to do things, she would."*** Another parent said, ***"I have a lot of support from my family and friends. It's been a year and they do remember (anniversaries and special days). Sometimes I want them around and sometimes I don't. What matters is that they remember her."***

The group agreed that the rules change all of the time. Grandparents need to get their support from other places after the death of a grandchild. Their own children just can't provide it.

After Marilyn's presentation, one parent said ***"My mum wanted to come over after my son died, but I couldn't think. I was in a daze. I didn't think she needed support."*** Denise reinforced the fact that ***"in the middle of grief you can't be an educator. People don't know the rules and don't know what to do and you (the parents) are not in a position to tell them at first. Being informed is a helpful thing, but it's also a challenge in how to do it."*** One parent agreed stating ***"we can now talk about things more. She's making an effort now that I've opened up to her to how I feel and have felt since his death. It's better now."***

### Fear of Further Hurt

Discussion of the evening included acknowledgement of grandparents, other family and friends' difficulty in not knowing what to say and the difficulty in sitting with someone in pain. Denise affirmed loved ones attempts at comforting their adult children by stating ***"upsetting your kids is ok. You're not going to upset them any more than they already are."***

Parents agreed stating ***"I prefer people to say something. It's the situation that upsets me."*** Another said, ***"They're uncomfortable because they don't know what to do if they upset you, but you're***



*already upset.” And others agreed “Being upset is ok.” “These are the circumstances and the facts. Nothing is going to change it.” “It’s not until you’re in that situation that you know what it feels like.”*

### Everyone Grieves Differently

Denise reminded everyone that “kids – of all ages – grieve differently. If you don’t cry it doesn’t mean you don’t feel pain. There is a lot of energy in there, but people express it differently. Some people talk, some don’t. Partners grieve differently. Neither is right or wrong.”

Each person has to come to terms with how another grieves and accept that this may be and often is different. This is especially true for grandparents. “When a child dies we have to survive first and then grieve. Sometimes we don’t look after ourselves in the best ways. It’s a shock reaction. Sometimes people think you are doing really well and then 2, 3, 6, or 8 months along and they think you are falling apart because you’re crying. It’s like by not crying you are doing well, except doing grief work well often means the opposite.”



We need to be able to cry and feel when we need to, not when someone says or thinks we should. “Death takes the ultimate control away and sometimes by not letting your parent have control you are trying to regain some control.”

### Some Helpful Strategies for Supporters

Some of the strategies that parents have found helpful since their child died have been:

Just be there – provide opportunities just to sit and listen – not give advice

Having my mother around. I wanted both parents to come, but only my mother could.

An acknowledgement and connection is needed

To include my child in their conversations

To acknowledge my child’s birthdays, anniversaries, mothers’ day and fathers’ day

To remember my child at Christmas

Buy or do something in remembrance of my child – for the garden, a card, a photo albums, a run, a walk, a tattoo, etc.

Practical help – shopping, cooking, looking at photos

Take time to listen – slow down and not

try to fix what can’t be  
We need confirmation of our feelings & support

Avoid suggestions that the care of the child was less than adequate

Allow time to grieve and mourn. (Three years is very common for it to be intense.)

Be able to listen and talk about his/her child & his/her pain without commenting about what they should or shouldn’t feel.

Accept the ebb and flow of terrible and not so terrible days

Allow everyone to grieve in their own way – whether they are a child, an adult child or grandparent

Ask your child how they would like to be supported

If there are siblings within the family, supporting them in their grief will also assist your adult child, as they may not be able to do so

Acknowledge that grief can strain even the closest of relationships

Get help for yourself – read books, join support groups, get counselling

Have some time away

Learn there is no timetable for grief.

### Our Thanks

On behalf of the parents attending the Family Bereavement Support Group, I’d like to thank Denise and Marilyn for a great evening’s discussion.

One parent summarised the group’s thanks by saying, “I understand the difficulties grandparents have better now. It can be confusing. They want to talk, but then they don’t want to. It’s confusing for all of us. The group sessions are good for me, because I know it’s not just me. I’m not alone. Lots of people feel the same thing.”

### Useful References

about grandparents and grief are:

[http://www.compassionatefriends.org/Brochures/the\\_grief\\_of\\_grandparents.aspx](http://www.compassionatefriends.org/Brochures/the_grief_of_grandparents.aspx)

**The Grief of Our Children** by Diane Mckissock

[http://www.bereavementcare.com.au/books/grief\\_children.htm](http://www.bereavementcare.com.au/books/grief_children.htm)

**Grandparent to Grandparent** – SIDS and kids booklet by and for grandparents

**Grandparent Grief a Unique Experience** – a brochure of the RCH Social Work Department

**You Can’t Win with Me** – excerpt from SANDS November 1992 newsletter

## Support Services

### Where to get help

- Your doctor
- Your local community health centre
- A trained counselor
- Lifeline 13 11 14
- Nurse-on-Call Tel. 1300 606 024 – for expert health information and advice 24 hours, 7 days
- Australian Centre for Grief and Bereavement – Bereavement Counselling and Support Service Tel. (03) 9265 2111
- Australian Centre for Grief and Bereavement – Kids Grieve Too; Younger Bereaved Partners Tel. (03) 9543 9449
- Mercy Grief Services Tel. (03) 9364 9838 – for people living in the western region of Melbourne
- Kids Help Line Tel. 1800 551 800 24 hrs a day seven days/ week.
- The Compassionate Friends Victoria Tel. (03) 9888 4944 or 1800 641 091 – 24 hrs a day, seven days/wk.
- SIDS and Kids Victoria Tel. (03) 9822 9611 or 1800 240 400 – 24 hours a day, seven days a week.
- Very Special Kids—Australia’s first hospice for children 9804 622
- SANDS (Stillbirth and Neonatal Death Support) Tel. (03) 9899 0218
- IDSA (Industrial Death Support & Advocacy) Tel. (03) 9309 4453
- Victims of Crime Helpline Tel. 1800 819 817
- Road Trauma Support Team Tel. (03) 9819 9922 or 1300 367 797

## Recently Bereaved Parents Support Group

**November 5th 7.30pm—9.30pm**

Seminar Room 2, 4th Floor  
Main RCH Building

## Day time Bereaved Parents Support Group

**December 3rd 10am—12pm**

In the Mackinnon Collaborative Practice Centre—Room 4, 7th floor, RCH South East Building



# *Straight from the Heart*

*This poem was written by a mental health consumer who was institutionalised over a number of years in Queensland. He wishes to remain anonymous.*

## **'LISTEN'**

When I ask you to listen to me  
And you start giving me advice,  
You have not done what I asked.

When I ask you to listen to me  
And you begin to tell me 'why' I shouldn't feel that way,  
You are trampling on my feelings.

When I ask you to listen to me  
And you feel you have to do something to solve my problems,  
You have failed me, strange as that may seem.

Listen! All I ask is that you listen;  
Not talk, nor do – just hear me.  
And I can do for myself – I'm not helpless  
Maybe discouraged and faltering, but not helpless.

When you do something for me, that I can and need to do for  
myself,  
You contribute to my fear and weakness.

But when you accept as a simple fact that I do feel what I feel,  
No matter how irrational  
Then I quit trying to convince you  
And can get about the business of understanding  
What's behind this irrational feeling.

When that's clear,  
The answers are obvious and I don't need advice.  
Irrational feelings make sense when we  
Understand what's behind them.

Perhaps that's why prayer works sometimes for some people;  
because God is mute, and doesn't give advice to try to 'fix'  
things,  
He/She just listens, and lets you work it out for yourself.

So please listen, and just hear me, and if you want to talk,  
Wait a minute for your turn,  
And I'll listen to you.

Source: <http://www.health.qld.gov.au/mhcarer/docs/articlelisten.pdf>



*Our letter box is waiting!*

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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Phone: 03 9345 6111  
Or email: [karen.ditty@rch.org.au](mailto:karen.ditty@rch.org.au)

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

**Thursday 19th November**  
**7:30 pm – 9:30 pm**  
**Seminar Room 2, 4th Floor**  
**Front Entry Building**  
**Royal Children's Hospital**

In the **November Group** we will be  
joined by Geraldine Page speaking about  
"Rituals"

In the December Group we will have a  
guest speaker from Very Special Kids  
speaking about "Self Care & the  
Importance of Remembering Ourselves  
When Remembering During the Festive  
Season".

It will be an interactive creative evening.  
**Please join us.**

*The newsletter is always a team effort. Thank you to our guest speakers Denise Same and Marilyn from SIDS & Kids, Carol Quayle for co-facilitating the Group, and to our skilled committed Admin Team- Carly Blanche, Rebecca Welsh and Sam Harris.*

*Karen Ditty*  
Editor