



FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department
Royal Children's Hospital

NEWSLETTER SEPTEMBER 2009

Welcome to the Royal Children's Hospital's Family Bereavement Support Programme's September Newsletter. This month's Newsletter includes an introduction of the new RCH Bereavement Services Coordinator, a summary of group notes taken during the September Group evening, without participant names, as well as quotes from books used from the evening's topic, "How I Share My Life with Others: the private and the public me".

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

'How I Share My Life With Others: the private and the public me'

At the September group, Carol Quayle, Manager, Palliative Care Services Mercy Palliative Care, led the discussion on this topic, which focused upon how we experience and share our grief with others in our communities and how what we feel on the inside may be very different to what we share with those around us. The evening's group was an opportunity to explore how we, as parents, present ourselves to the outside world, how we are perceived by the outside world; and what we want the outside world to know about us, our experiences, and our children.

Carol used quotes from several books to support the topic's exploration and discussion, beginning with Dianne McKissock's *The Grief of Our Children* (1998):

"Children represent our hopes and dreams of the future, our stake in immortality. When a child dies we may all, at some level, experience a sense of failure. As parents, as family members or friends, or as members of society, we may feel as if we have failed in our responsibility to ensure the child's safe passage to adulthood. As a result we may feel



incompetent, lose self-esteem, and at a practical level, experience the loss of a role. Existentially, we grieve the loss of potential, our hopes and dreams of the future.

A child's death, even an adult child's death, violates assumptions about safety and justice, and perhaps of religious beliefs.

Whatever the age of the child or the age of the parents, the death of a child is a painful and difficult experience. Some writers suggest that the first year with its 'firsts of everything', is the worst. Yet bereaved parents insist that every subsequent year is difficult, each with its own memories, or thoughts of what might have been, each with its own anguish." (pg. 105)

A Time to Grieve

One of the themes for the group discussion was about how it is normal for the grieving process to be an ongoing one and how feelings of grief can remain quite intense for quite a long time. The group discussed and validated each other's experiences and differences. **"It doesn't get easier. I still think of him**

every day." *"The first year was the hardest. It was the first of everything. After that first year, I knew what I was going to go through and also knew how to prepare myself."* *"The first year we had a memorial service for her. This year we're just going to go away."* *"She's still with me every day."* *"The first 6 - 12 months was the downhill slope. It became different after 12 months and to lift a bit."*

My Fit & My Child's Fit in My Community

In Sobonfu E. Some's book, **Falling Out of Grace**, she states that it takes a village to raise a child. In her book, **Welcoming Spirit Home**, she continues in this theme by discussing how each person contributes to the whole of society. *"The community concept is based on the fact that each person is invaluable and truly irreplaceable. Each person has a gift to*



give, a contribution to make to the whole. The kind of gift a person brings, the kind of being a person is, is very unique to him or her and is valued by the community” (pg. 32).

Births are commonly celebrated by our families, friends, colleagues and communities around us. Unfortunately, often these same communities don't know how to respond to the death and loss of a child. People in the community, even those closest to us, often do not know what to say or how to say it. They don't want to make us cry or make our situation worse and so, many times, they say and do nothing.

Who is Supporting Who When it's Needed?

The group spoke about their experiences of responses to and from their communities. A key theme was that parents felt like they had actually provided the support to others, instead of feeling supported. *“I felt like I was supporting my community instead of them supporting me.”* *“With the in-laws not coming to the Memorial Service, it felt like they were not recognizing our son and I had to say something. I had to tell them about how they don't talk about our son and how we feel shut down sometimes by them when they talk of the other grandchildren, but when I mention our son they change back to talking about the other children. I needed to tell them how we feel. They responded by saying that they don't know what to say and don't mean to shut us down. I'm glad I said something. People need guidance. Saying something was a lot better than wasting all of that energy being upset and taking it out on others who aren't involved.”*

Parents talked about sometimes wanting to acknowledge their child and their



memories of life with them in their conversations with those around them, and also how this is often difficult. *“Sometimes we feel hurt when they don't talk about him. They avoid it – not to make us feel sad or bad, but we want to talk about it.”* *“Not acknowledging is really cruel. You learn really quickly who is good for you to be around and who is not good for you.”* They spoke of difficulties that happen when you do open up and talk. *“I like telling people about my daughter, but have to include that she died, otherwise they assume that she's still growing and doing things like their kids.”*

During the group, parents highlighted their awareness and understanding of different grieving processes and how needs happen at different times for different people, even parents of the same child. One parent summarized it, *“... sometimes between us, one person wants to talk and the other doesn't want to. You want to help the other person feel better, but you can't. You can't change it. You can't make it go away.”*

Changes in Clubs

The group explored how our sense of community changes when you have a child. What people talk about, their discussions, connections, and social group links are focused more on what is happening with you and your child, not just you as a person. The person has become parent and joined the community of parents, families and children. There is a distinct change when a child dies.

Parents discussed that when their child died, *“it felt like a divorce.”* You separate from that parent & families community, especially if this was your only child. *“I don't have anything in common with them any more. The next stages are still happening for them, but not for me or my daughter.”*

Many in the group spoke of how being part of the Parent Bereavement Support Group was *“a safe place... a safe space.”* *“Here I can talk about it. For the first year, it was really clunky – just so hard. After 10 months, I am*

able to attend the group now. People understand here. They know.”

Parents talked about how in the broader community often people, especially the general public, did not respond appropriately. One parent remembered, *“When your child's sick you're part of different clubs: disability, health departments, specialists, etc. The hospital was our community, where in a shopping centre people would make stupid comments. They were so ignorant and didn't understand the tubes.”*

It is widely acknowledged that grieving is a process that takes time and is different for each individual and each situation. It is important to give ourselves time and space to be able to feel and acknowledge the loss of our children. It is up to each individual what you decide to share with others.

Parents in the group spoke of the need for change of expectations of parents in the community, *“People have to change their expectations after a child dies. We are entitled to stay at home and not go out if you don't want to.”* *“We shouldn't have to put on a show for everyone.”*

Sharing Inside & Outside – different sides for different groups & times

The group explored what they share publicly about their lives after the death of a child and what's kept private. They did this initially through a creative activity and then shared and discussed it as a group. They spoke about how the death of a child violates the sense we have in the natural course of life that the older people will die first, not the younger and not your child. *“My thoughts are all over the place and I'm still trying to come to terms with it. She lived. She was here and she was beautiful. She was loved and had the biggest heart they'd ever seen... Inside it's like “Hello, can anybody hear me?” Her death has really messed with my head. It's hard to express how disappointed I am and how people have let me down.”* *“I can kind of talk about it, but can't share the depths of my feelings. I can talk, but can't really*



explain how to pick up the pieces as life will never be the same.”

For some who had experienced the death of their only child, they also talked about how they experienced a change in role, of being a parent and then not. The loss of role and identity compounds their grief experiences. *“I put myself together during the day, but there’s a hole on the inside filled with pictures of my daughter that they don’t see. I’m not used to being so vulnerable.” “It continues to be all about him. He was a gift to us and continues to be a gift to us. He was always smiling and it’s what we remember and what we’re about. On the inside, we’re trying to deal with it... We’re eager to be parents again. Now is a time for us to dream again, but inside it’s still hollow and still feel a lot of confusion.”*

Regardless of what we feel we have gained from our experiences of life with a child, there remains a mixture of emotions after his or her death. *“I sometimes feel guilty. I feel more freedom as I no longer have all of the problems we had and am no longer up all night. I can do things I couldn’t do for years. This is so much easier practically now, but I still miss him.”* Another parent spoke saying, *“I enjoy moments and people think I’m coping, but yet on the inside I’m not all the time.”* Still another parent stated, *“I can easily see how people drink to get a bit numb, but know that is not the way to go.”*

Parents in the group talked about the changes they had experienced in the different areas of their lives. *“I went back to work after 2 – 3 months and people expect you to be the same.” “You learn to move with it, but you are never the same person again.” “We’ve sustained so much. I’ve delved into the depths of my courage and am constantly trying to get through it.” “I was depressed and needed medication*

for a while, but realize that it’s not the worst thing in the world.” “You keep changing gear and don’t realize you’re doing it while your child is sick and then, afterwards, you’re still doing it, trying to cope.” “There are daily responsibilities at home and at work. There are the practical things you just have to do, but it is so hard and people just telling you that this is part of life, but it shouldn’t be part of life. Dying at 80 is part of life, not this.”

As a result of their experience with their child, some parents reported an increased awareness and appreciation of children and their place in the different communities in society. They spoke outwardly of feeling enriched through the process of having known their child and shared *“I appreciate children more now, especially those with problems. I think it would be nice to help other children now and have a whole other way of looking at things now.”*

In Conclusion

Carol concluded the group with the following quote:

Losing someone we love is an initiation. Our life changes. It is not going to be the same again. All our relations with other people and ourselves are forced to shift. We become a new person. Although a part of our heart breaks, the spirit of the departed remains. Through that spirit love continues to flow, helping to show us the way, if we allow it, to the higher states of grace and wisdom we were born to reach.” (from **Falling Out of Grace** by Sobonfu E. Some 2003: p.140)

Parents in the group reported finding the evening’s topic very useful. They stated their enjoyment of being able to do a creative activity that expresses how they feel and how it helped them discuss the difficulties they have in expressing their thoughts, feelings and experiences to the different people around them. Further group discussion and catch ups happened after the topic’s conclusion over supper.

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.
- 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

Introducing

Karen Ditty has recently joined the RCH Social Work Department as a Senior Clinician with the role of Bereavement Services Coordinator. Karen is an experienced Social Worker and Child & Family Therapist, who comes with many years experience helping children, adolescents, individuals, couples and families on a variety of issues including bereavement and its impact on our lives. Some of her responsibilities include providing counselling, coordinating the support groups and connecting people to services in the community. Karen edits the newsletter.



Straight from the Heart

As Time Goes By... has been included in this month's Straight From the Heart by Kyana Lipscombe. This poem was written by Kyana for her little brother Xander Oliver Gould to commemorate his 5th year anniversary since his passing.

AS TIME GOES BY...

Little boy so full of grace
 I can trace the image of your face
 Little boy forever young
 While I have come completely come undone
 In my head and in my heart
 Time cant erase that we are now apart
 Year after year I wish you were here
 As reminders of you are always near
 I cling tightly to the images of you
 but yet I cry why should it be me
 I ask myself why
 There is an aching darkness, an irreplaceable hole
 all I want to do is hold your hand
 but reality crumbles like hardened sand
 I remember the soft scent of your hair
 it hits me with a darkened despair
 Your little laughter is with me ... its all I hear
 it resonates with me until it creates fear
 Your brown chocolate eyes are vacant and gone
 A family life of once was is what I long
 My memories have become faint of you
 I search to see if they are mine or untrue
 Brother dear I need you so much
 Its a reality of life I know I will never touch
 As time slowly goes by the pain remains
 No one is at fault and no one to blame
 I cant fill the void and take your place
 The memories of you will never erase
 Now I slowly grow up and not alone
 We fill the emptiness of you in our home
 I need to move on, have space
 To live again and find a happy place
 Take a deep breath and let go
 For a life with you I will never know

Forever in my heart, my soul and memories my little brother

Xandar Oliver Gould
21/06/2002 - 22/10/2004



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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Or email: carly.blanche@rch.org.au

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

Thursday 15th October
7:30 pm – 9:30 pm
Seminar Room 2, 4th Floor
Front Entry Building
Royal Children's Hospital

In the **October group** we will be joined by Denise Same from SIDS and Kids and a grandparent to talk about the topic "**Grandparents Grieve Twice**".

Grandparents are welcome to attend to share their experiences.

The **November Group** topic will have Geraldine Paine speaking about Rituals.

In the **December Group** we will have a guest speaker from VSK speaking about self care.

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

Karen Ditty
Editor