



# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department  
Royal Children's Hospital

## NEWSLETTER AUGUST 2009

Welcome to the Royal Children's Hospital's Family Bereavement Support Programme's Newsletter. This month's Newsletter includes the stories of two parents, Liat and Rob, who spoke at this year's Annual Memorial Service. Also included is a summary of the August Meeting of the monthly Bereavement Support Group and a poem written by Carla Caiolfa in memory of her sister Monica Marie (25/05/1990 – 07/09/1997). We hope that as you read the words of these family members that you will find comfort, support, reassurance, connection and hope for the future.

### **“MY PATHWAY”** *Two Parents' Reflections during the RCH Memorial Service*

On Sunday the 30<sup>th</sup> August the Royal Children's Hospital's Memorial Service was held. This Service remembers and acknowledges those children who have died at the RCH. The theme for this year's Service was 'My Pathway'. The day was shared by over 300 family members, friends and staff of the RCH. For the first time during the Service, two parents, Liat Harrower and Rob Tait, shared the story of their pathways of grief – their stories appear below.

As bereaved parents you share something of a common journey – you have travelled an unwelcome pathway, and experienced the life and death of a child who held a very special place in your hopes and dreams. Though there is a shared aspect to the journey which unites all of you, you have travelled pathways unique to your own journey.

Liat and Rob spoke of their own journey and showed both the common and unique aspects of those journeys. Thank you to both Liat and Rob for their courageous and heartfelt speeches and for letting us include their pieces in this month's newsletter.

#### **“GRIEF TO HOPE”: Liat's story**

*... My son Mitchell died just over one year ago. He was 7 and a half years old and had an incurable condition called Niemann Pick Type C. Having been born with an enlarged liver and spleen, tests were carried out to get to the bottom of it, and we got the diagnosis at 6 months of age. It was, quite literally, a death sentence. There is no treatment or cure for the disease, and many children do not survive their school years.*

*Mitchell developed normally until the age of about 6, and then rapidly unlearned everything he knew. He went from being a very active, happy, full of life child to being totally wheelchair bound, tube fed, unable to communicate or even roll over in bed. All within about 18 months. The combination of the*



*pressure of his care, the sadness of what was to come and differing styles of handling our grief, also brought about the end of my husbands and my marriage at this point. A story sadly too often played out in such circumstances.*

*Mitchell's final months were spent on oxygen and needing morphine. His final 24 hours will stay in my memory forever. He stayed at home with us until the final day, when, totally unready for what was about to transpire, I took him to Very Special Kids in Malvern.*

*By the time the ambulance arrived at VSK, during that 45 minute trip, I realized what was about to happen. That which I knew was going to happen, which I had been preparing myself for, but can NEVER be accepted. The impending death of my much loved son.*

*I slept with him in a double bed that night, an oxygen mask separating us, then in the early ours of the morning of the 10<sup>th</sup> August 2008, surrounded by those closest to him, he opened his eyes briefly and looked at me. I whispered to him that it was "all right – we're all here with you honey, we love you so much – it's okay if you need to go now". Moments later he took a breath.....and then didn't take another. We all fell silent, hoping against hope at that last moment for a miracle.....another breath..... which would lead on to another. Another minute, another*

*day, another lifetime. But of course it was not to be. He had chosen his time, and this was it. Another breath did not come.*

*I held him for at least half an hour after. I bathed him and washed his beautiful auburn hair. He had so loved being in the bath – it was a place of great joy to him. I talked to him, I brushed his teeth, and combed his hair. I put on his warm pyjamas because it was a cold day. We then tucked him into a beautifully prepared bed, surrounded by his favourite stuffed toys – Maisy and Muffin and Pooh Bear, turned on his favourite music (he could NEVER be without music), stroked his hair, held his hand and talked to him.*

*It was so hard to leave that room. To close that door behind us.*

*How do you explain all this to someone who has not experienced it? It is like describing parenthood to those who have not had a child. You can only give them words, knowing that some things are unknowable until you have lived the experience. I know that you all here in this room know – truly KNOW – what I mean.*

*I could not have believed at that time that I would ever recover from this tragedy. That there would ever be a time when my heart would stop physically aching in my chest. That I would ever accept life as being anything other than a huge, mocking trick – something to be endured in utter sadness until I was set free by*

*my own death. That I would find true happiness, joy or beauty again would never be a possibility.*

*And in all honesty, those things are still a daily struggle for me. I expect they always will be at some level.*

*But a strange re-awakening has started to happen over the course of this past year.*

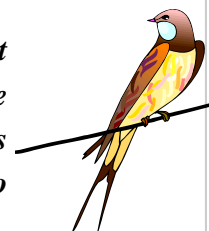
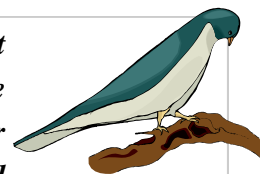
*While appearing to be in control, getting on with things and putting on the bravest face that make-up and a big smile will allow, I have gone through the deepest periods of depression I have ever experienced.*

*Black holes of emptiness, hopelessness, self loathing and loneliness that have brought me to the brink, literally, and yet I have survived them.*

*When I come out of them, the world is still turning, my other children are still growing, babies are being born to friends, or there are 2<sup>nd</sup> (or even 3<sup>rd</sup>!) marriages taking place.*

*The beautiful warble of a magpie from the front lawn will sometimes stop me in my tracks, and bring me to a state of almost immeasurable joy just by its melody.*

*A shaft of sunlight will temporarily pierce through the clouds and warm my body to*



*the bone on a cold day.*

*The 5<sup>th</sup> generation of swallows have taken up residency in my garage to bring forth the 6<sup>th</sup> generation, and once again I grumble inwardly about not being able to use it for my car because of the little 'birdy-surprises' they leave on it. Yes, I COULD get rid of that nest, but then, where would THEY go ?*

*I will catch the eye of a child in a shop and smile at him. He always smiles back. He will look back at me again and again as our connection continues and we both receive the same joy. The joy of occupying this place at this time. Of just being.*

*I have learnt to not just FIND, but to actively LOOK for joy in the smallest of things. In fact, the smaller the better. There's something to be said for that old saying about looking after the small things and the big things will take care of themselves. I am gradually finding that I am piecing together enough little things that my heart is finding a certain joy in keeping on beating. And the more I have done this, I am coming to a realization that this is exactly what Mitchell did – he found incredible joy in the smallest of things. His gorgeous giggle would escape at incomprehensibly small things.*

*I am learning to keep bringing myself back to the present moment, to not dwell on the past too much, thinking that it somehow 'makes me who I am'. To not worry overly about the*

*future – be it a year, a month or 10 minutes from now – it keeps me from experiencing life right now....it might mean that I miss out on seeing or experiencing something beautiful. Something that Mitchell would not have missed. He was, as all children are, very wise in this area.*

*He remains a part of my everyday life, we talk about him openly and warmly, acknowledging the huge presence he was in life and the amazing role he continues to play between the world we know and another now.*

*So, today I stand here one year and 21 days after my son closed his eyes for the last time and took his final breath. Yes, I wish he was back here with me. Yes, I wish a miracle had happened and he had been cured. Yes, I wish this had all just been a very bad dream. But it wasn't.*

*I am still here. I am still alive. I am perhaps more alive than I have ever been. In all honesty I cannot say I am often 'happy' in the traditional sense, but I have many moments of profound contentment, and appreciate life so much more than I ever did because I am finding joy in things I failed to notice before.*

*And that is a good start I think.*

*My hope for all of us here today, is that we are able to search out and find simple joys in our lives and appreciate them for the huge miracles they can be. To honour our*

*little ones by noticing the things they would have noticed - that would be putting smiles on their faces – and smile for them.*

by **Liat Harrower**

Mum to Mitchell (9 Oct 2000 – 10 Aug 2008)

Also.....

Taylor 10 years

Travis 24 years

Rachael 25 years

**“GRIEF JOURNEY”:** Rob's story

*The last time I spoke in a setting like this was a bit over four years ago at my daughter Olivia's funeral. Olivia died in April 2005 after 2 weeks in intensive care*

*The difference is that everyone at her funeral wondered what it must have been like to tragically lose a child – and here, everyone knows. Everyone knows the whole range of emotions – aching chest, churning stomach, the isolation, the sense of missing, the disbelief, the unfairness, the despair, and the fear that you'll forget.*



*'Journey' is a good way to describe the last four years, but for all the things that have changed over that time, the one thing that has not changed is that I still miss Olivia as much today as I did when she first left us. She was a remarkable kid.*

*Now like most journeys, you don't really know how much progress you've made until you look back and see how far you've come. Even if it seems like you're getting nowhere, when you look back it's surprising to see how much distance you've covered. I can do things now that I couldn't do a year ago or even 6 months ago. Whether it's a big thing or a tiny thing, they're all milestones that show you that you really are making progress.*

*That's not to say there aren't days when the only option is to sit on her bed and have a cry, but for me, the journey now is a little bit softer and gentler compared to the early days. Those first few months for me were like violent waves of grief crashing on you and it would physically hurt. Now, the grief is more like the tide gently coming in and going out again. It's a bit more predictable. You mostly know what to expect.*

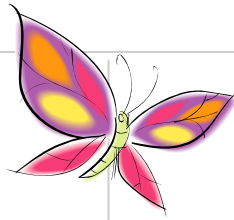
*When she was in grade one, there was one school night when my wife June was unpacking her lunch box. As she took out the uneaten sandwich and the banana peel, she also found her diamond engagement ring that Olivia had taken to school for show*

*and tell. When June challenged her on it Olivia said "but Mum, they adored it".*

*In the first year after Olivia died that would have been a painful story and a painful memory for me. And to think of it would just remind me of everything we were missing out on – how funny she was, how lovely she was, how kind she was. In the early days there weren't any happy memories – every one was a painful reminder that once we had her with us but now she was dead. But four years on I can at least smile at a story like that, and with all the other great stories that go with it.*

*At four years into this journey I think we're getting closer to the time when we're able to enjoy her memories without having all the nasty images of her last two weeks come back to us. Whether that will take another year or two or five years maybe someone here can tell me later. Will we ever be OK when Eric Clapton's 'Tears in Heaven' come on the radio? I don't think so, but when I look back at where we've come from I know we've made progress.*

*I realized something pretty significant soon after the fourth anniversary of her passing. For the very first time since she died I felt sure that eventually – not yet – but eventually, we would have peace over this. That even if we're always sad, that we will eventually find a peaceful*

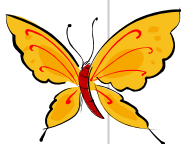


*acceptance of what has happened. In the early part of the journey I thought that would never be possible, in fact I honestly thought I wouldn't survive – it was just too big and the prospect of the next 40 years without her was too much to think about. So we've taken it one day at a time, for about 1600 days in a row, and now I think we are going to survive. We've still got a lot of ground to cover – but we will get to the stage one day, where we can live with this peacefully.*

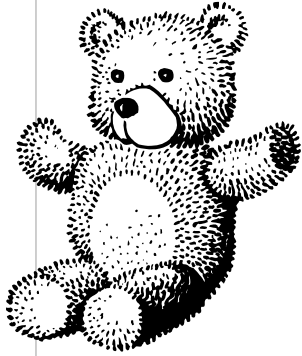
*And between now and then I want the things that I do to be a legacy to her because having a child that's died before you doesn't mean you can't live a life well lived. In the early days after she died it was all about me and my grief and my loss and my pain. But now I get some satisfaction out of looking outside my own complaints and seeing how many other people are doing it tough, and if I can do something to help, then I feel like that's a legacy to her kindness, and that way a part of her can live on.*

*I'll really look forward to seeing how much progress we'll all make by this time next year.*

*by Rob Tait*



# *Kids Grieve Too: How can we support our other children?*



Augusts' Parents' Bereavement Support Group was co-facilitated by Carol Quayle and Colin Charles, Social Worker with the Bereavement Counselling and Support Service of the Australian Centre for Grief and Bereavement. The discussion focused upon the grief experienced by bereaved siblings, and how parents and others can support them.

One of the main themes of the evening was the question of how parents differentiate between being over protective of their grieving children and maintaining role boundaries, routines and 'rules' around what are appropriate behaviours and attitudes at certain developmental stages and ages. As one parent said: *"I think, at first, we overcompensated. We let our nine year old son get away with more than he would normally get away with. We said 'yes' to things we would normally not have. It's been hard to pull the reins back in"*. It is interesting to note that one well known writer about grief, Atle

Dyregrov (1994) states that *"after a child's death, increased personal anxiety for surviving children, often with resulting overprotection (and overcompensation) is very common."* Knowing early on that this overprotectiveness is natural and normal can be helpful for parents. As one parent in the Group said: *"It's natural to protect your kids"*. However, as another parent added, in her opinion, *"Consistent rules are a must."*

## **A glance at the literature:**

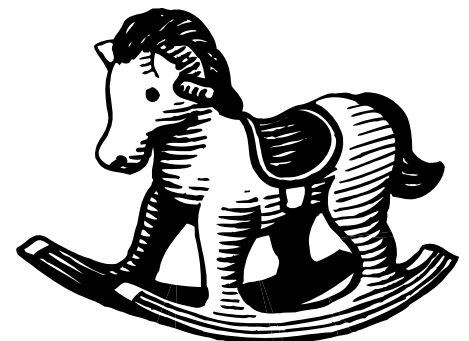
### **The early days, weeks and months:**

Following the death of a sibling, writers such as Dyregrov (1994) have found that children experience immediate reactions similar to those experienced by adults. These reactions include feelings of shock, disbelief and a sense of unreality. Withdrawal, loneliness, changes in appetite and sleep disturbances are common in children following the loss of a sibling. For school-aged children, study habits may change, and concentration difficulties are frequently experienced.

### **Maintaining a continuing bond with the sibling who has died:**

Researchers and authors Silverman,

Nickman and Worden (1992) describe grief in children as *"a process ... where the loss is negotiated or renegotiated over time as the child develops and can view themselves and others differently at different developmental levels."* They describe how *"children develop an inner construction or representation of (their sibling who has died), and how this facilitates their coping with the loss as they continue to keep (their brother or sister) present in their inner life in various ways."* Children and adolescents often keep something personal that belonged to the brother, sister or friend who has died. This might be an item of clothing, perfume, a piece of art or craft created by their sibling or friend. Photos and videos are also important and remain treasured objects into the future. As one parent in the Group said: *"Often it's not until VCE when kids are asked to write about something significant*



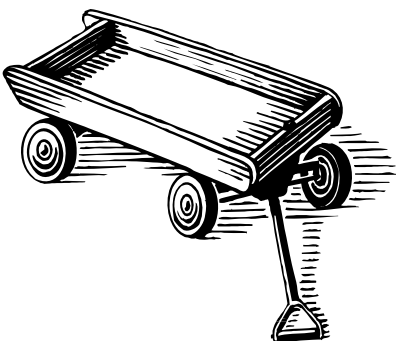
*that has happened in their life, does the extent of the grief come out*". Writing is another way of maintaining a continuing bond with the person who has died.

### **Friends grieve too:**

One parent told the Group that when her adolescent son was very ill in Hospital, some of his school friends came to see him. They were **"devastated"** when he died. In some respects, the grief of friends of the child or adolescent who has died is often overlooked. As Dyregrov (1994) writes: *Unfortunately, few studies have looked at grief among friends, in spite of the intense relationships with peers, such as best friends, boyfriends and girlfriends, particularly in adolescence.*

### **What helps grieving children?**

A home climate of consistent care and support is important for bereaved children and adolescents. However, at a time when the demand for attention and care is high from the child's side, you as the parent may be functioning below your ordinary capacities because of the effects of grief and/or trauma. It may be helpful to enlist the aid of a

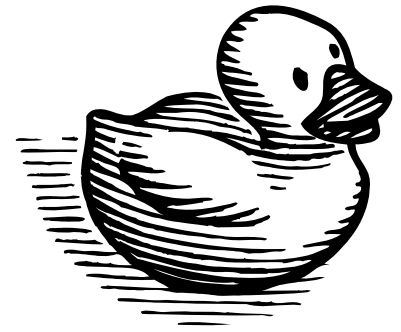


trusted and supportive relative or friend to provide some one-on-one care for your child for a short period of time.

Dyregrov (1994) goes on to say: *"Ensure that the child gets adequate, honest, open and age-relevant information and facts about their sibling's illness and death ... Identify any misconceptions, misunderstandings, misperceptions and magical thinking that may be creating difficulties for (your) child."*

Try to be aware of your child's developmental stage, his or her understanding of death, and explore ways to support your child at these various stages. Children's understanding of death develops from a belief in the reversibility of death in the preschool years to a gradual understanding of the finality and irreversibility of death at age 6 or 7. As children develop and mature, their concepts surrounding death and bereavement change. You may find it helpful to speak about how your child's beliefs and understandings change over time with a professional associated with one of the support organizations listed towards the end of this Newsletter.

Ensure 'quality time' occurs between you and your child by planning positive events such as a regular bedtime story or chat, family meal times around the table, or a



family weekend away. Try to reestablish, as soon as you are able, routines concerning school, kindergarten and home to help your child regain a sense of security and order in the world.

Finally, try to give your child permission to grieve and create opportunities to share some of your own feelings, thoughts and reactions with him or her. This allows your child to normalize what he or she is experiencing. As one parent in the Group explained: ***"As adults we are role models to our children, so therefore we become role models about how to express grief. If we bottle it up, they will too. And that's not healthy."***

To conclude, we hope you have found in this Newsletter some meaningful and useful information. Our thoughts are with you as you journey on your own pathway into the future.

Reference: Dyregrov, Atle (1994), "Childhood Bereavement: Consequences and Therapeutic Approaches", in *ACPP Review & Newsletter*, 1994, Vol. 16, No. 4

# *Bereavement Support Organisations which offer children's and siblings' groups*

**SIDS and Kids Victoria**  
**Ph. 9822 9611 / 1800 240 400**  
[www.sidsandkids.org.au](http://www.sidsandkids.org.au)

*A statewide counseling, education and support service for parents and families whose baby or young child (up to the age of six years) has died suddenly and unexpectedly from any cause. The child may have been stillborn (from 20 weeks gestation), died in the neonatal period, genetic abnormalities, SIDS, accidental death, fast onset illness or a pre-existing condition. In the Barwon and Grampians regions, the child who died may have been 18 years of age or younger. 24 hour telephone service, home visits, support groups, children's programme, Annual Red Nose Day Memorial Service, newsletters.*

**Very Special Kids**  
**Ph. 9804 6222**  
[www.vsk.org.au](http://www.vsk.org.au)

*Very Special Kids House is Australia's first hospice for children providing respite and end-of-life care. Provides individual and family bereavement counseling; networking and peer support; bereaved parent workshops, meetings and an annual retreat, sibling activities, Remembrance Day and newsletter.*

**Compassionate Friends**  
**Ph. 9888 4944 / 1800 641 091**  
[www.compassionatefriendsvictoria.org.au](http://www.compassionatefriendsvictoria.org.au)

*A self help, statewide service which offers a Bereaved Parent Support Centre, 24 hour grief phone support, suburban and country support groups including a Sibling Group, and a bimonthly magazine*

**Bereavement Counselling Service**  
**Australian Centre for Grief and Bereavement**  
**Ph 9265 2111**  
[www.grief.org.au](http://www.grief.org.au)

*Provides counseling and support for bereaved people including parents, siblings and grandparents. Support groups and 'Kids Grieve Too' (activity based sessions for bereaved children).*

**Mercy Western Grief Services**  
**Ph. 9364 9839**

*A bereavement counseling and support service for people living in the western suburbs of Melbourne. Offers a monthly "Kids Grieve Too" programme*

# Straight from the Heart

This poem was written by Carla, a ten year old girl, in memory of her sister  
Monica Marie Caiolfa  
25/05/1990 - 07/09/1997  
Thank you Carla, for sharing this with us.



*I AM...*

*I am a nine year old girl, who has not met her big sister,*

*I wonder if Monica can come back to life,*

*I hear Monica talking to me,*

*I see her right next to me,*

*I want her to come back to life and not be sick,*

*I am a nine year old girl who has not met her big sister,*

*I pretend that I know every-  
thing about her,*

*I feel her touching me at night,*

*I touch her but I touch air,*

*I worry if I'm not a good sister*

*I cry because I miss her,*

*I am a nine year old girl who has not met her big sister,*

*I understand she was sick and how she died,*

*I say I want her to come back to life,*

*I dream someday I wake up and it's all a dream,*

*I am a nine year old girl who has not met her big sister.*

By Carla Caiolfa, 3 Red



*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: [carly.blanche@rch.org.au](mailto:carly.blanche@rch.org.au)

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

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

In the September Group we will be joined by Carol Quayle. The topic will be **"My Inside, Outside or Private, Public Face"**  
This will include an activity and opportunity for creativity and sharing in a parent's life after the death of a child.

**Please join us in September**

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

Vivienne Bateman  
Editor