

FAMILY BEREAVEMENT SUPPORT PROGRAMME



Social Work Department
Royal Children's Hospital
NEWSLETTER MAY 2008

A very warm welcome to the May newsletter of the Family Bereavement Support Programme. As you read the newsletters and join in the groups of the Programme we hope that you will find support, connection with others and resources to help sustain you as you grieve for and love your child.

A Change in Priorities: reflections on expectations and a changed life when a child dies

We welcomed the parents who formed the May evening group. Before introducing our guest for the evening, Ms. Leanne Fink, and moving on to May's theme we took a few moments to acknowledge the parents, their children and experiences. We also *introduced* the group and some *practicalities*.

The group aims to offer a safe place where parents who are grieving for a loved child can meet with other parents. The Group is a space and time to explore together ways of living with change and loss. In the group parents are invited to share what they want to of their family story. Parents are most welcome to come and go from the group as they feel helpful.

"I feel closest to (child's name) when I am here".
"I need a place to do that (talk about their child and their grief), it's here, it's sad but there's like minded people".

Each PBS group is both similar and unique. This reflects the parents and their experiences. For instance in the May

group one parent was coming for the first time just a month after his child had died, another was joining the group for the first time almost a year since his son's death and several parents were returning after some time away from the group.

Parents are encouraged also to be a part of the group in ways they feel comfortable. This may be through listening, talking, questioning and wondering out loud. There may be times when parents want to talk more privately about their experiences or concerns. This could be with a trusted friend, family member or support person. Jane and Vivienne Bateman, (Bereavement Services Coordinator, RCH) are able to meet with parents at the Hospital or talk over the phone. They can be reached through the Social Work Department on 03 9345 6111. During the group Jane takes notes without names to help form the newsletter. The newsletter provides a resource for families and those who accompany them as they grieve.

It was a pleasure to welcome and introduce Ms. Leanne Fink to the



Parents' Bereavement Support Group. Leanne brought to the group precious and illustrative anecdotes from her family's experiences and through being a parent supporter at SIDS and Kids. Leanne's topic had emerged from hearing from parents who are bereaved about how their life changes so dramatically after their child's death. Amongst other things, priorities, relationships and *ways of being* can be transformed. As a way of beginning conversation on this theme we asked parents if they would be able to introduce their children *who joined us* in the May group.



Our children: Ourselves

"I'm the mother of..."

The children were introduced through words and photographs. As parents spoke about their children we had windows into the lives that had been shared. Through their parents' words the unfolding impact of the children's death was clear. The children were described as **"bright, bubbly, generous"** and a parent commented **"how well she lived her life inspired me"**. In the May group parents talked of small babies who had spent their brief lives in hospitals, infants with rare and complex medical conditions and adolescents whose lives had ended through leukemia. Parents also described how through their children's lifetimes' they had experienced short periods of great happiness **"4 days where we thought she'd be ok"**, the moments when there's **"one day you think they've turned the corner"** and spoke of being told there was an **"80 percent stat that she'd survive"**. **"The loss of a little boy and all the dreams"** is how one mother expressed her grief. Most parents in the group had been on a whirlwind of emotions during their children's illnesses. Several parents talked about those **"quality of life discussions"** and the **"hoping things will be different... trying to find hope when there was none"**. When parents introduced their families we heard that one family had two children

die from the same extremely rare condition. An occurrence which is unfathomable. In the May group parents had been living with their grief for differing periods of time. For some it was only several months since their child's death while for others it was a little over four years. Following their children's death most parents were grappling with seemingly unanswerable questions. As one group member said **"we're left with the unknowns, the queries, the maybes, it's the hardest thing, the giving up... feeling they'd be different (and beat the odds)"**. Yet despite the bleakness of grief, there were threads of emotions and moments that seemed to sparkle with love and gratitude. The group listened as parents said **"how grateful we are we got to know her and to tell her that we loved her"**. The parents were proud of **"what she gave people"** and said **"I miss her still"**, and the spirit of little babies who **"waited and waited and waited"** for a family member to arrive before they died. Whether their children's lives were measured in days or years the parents were thankful for them: **"we're very grateful"**.

After meeting with the children of the group and hearing something of their story Leanne then spoke a little about her experiences. After this she very generously asked parents if there were questions they would like to ask of her. This is something of Leanne's story and the conversation which followed.



Leanne and her family

Leanne's first child, Alex "a gorgeous boy" was born in October 2001. Leanne described him as "a very happy baby". On New Year's Day 2002 aged eleven and a half weeks Alex died. Alex was taken from his home to Monash Medical Centre. The cause of his death was Sudden Infant Death Syndrome. Alex's death was a shattering and life changing *event*. Immediately after Alex had died Leanne and her husband "couldn't bear to go back home", so for three months they stayed with Leanne's sister. Leanne explained how shortly after Alex's death George strongly wanted to sell their home. However

as it happened Leanne and George had six months in Queensland on a project for George's work. Then as Leanne said, "it was kind of nice to go back home... to the house with the memories". She continued "once you've had the services, all the support, people go on with their life but you're not; you're forever changed... they wonder why you're still upset". She talked with the group about how "life changes so significantly" when a child dies. A thought which will strike a chord in many parents' hearts. Following Alex's death Leanne described how "the coping mechanisms I took for granted to work they were not automatic... I needed to try; it took all my energy to get out of bed and to want to get through the day... I couldn't fix myself; I couldn't bring back Alex; I wondered what I'd done... there was the guilt, had I failed him"? Connecting to these thoughts a mother in the group would reflect **"I'm getting to the point where I want to be able to say it's a sad loss but it's not my fault. I need now to find ways to make my life meaningful, to make her life count for something"**. She later extended this conviction saying **"I want her life and death to make a difference to me. I knew I had to make sense and meaning to make it worth something... I had to push through and not sink"**. During the evening's conversation Leanne noted that while she and George were "grieving differently and at different times", they were still able to support each other, "we kept each other going". In a relationship there has to be a way to see "the common ground and see the other person's point of view" Leanne observed. Early on Leanne found it was really "important to talk about feelings". Initially as was mentioned earlier Leanne was very ill with her second pregnancy. This too impacted on her first experiences of grief at Alex's death.

Leanne went on to share with the group how after



Alex's death she and her husband George decided to have another baby. However,

unbeknown to them at the time, Leanne was pregnant. It was an ectopic pregnancy and Leanne became very ill. It was a harrowing time for Leanne and George. At about a year following Alex's death Leanne and George had the first of their three daughters, Laura. Laura who is now five was joined two years later by Jessica and then Abbey who is 20 months. In speaking about her subsequent pregnancies Leanne mentioned how for her and George there had been "a long journey, with different griefs along the way".

Love, Life and Changes

Before Alex's death because of her personality, Leanne said, she was "something of a *Dorothy Dix*" amongst her family and friends. People would bring to her "their problems and issues" but in her grief it was difficult to continue in this *role*. Leanne found that the "emotional needs of other people were hard to meet". "Along the way," Leanne said "relationships changed, some were lost and some over time got back on course". "In relationships" Leanne observed, "people say the darndest things... stupid things". For example people would comment about the apparent gender *make up* of Leanne's family "*Three girls, wouldn't you love a boy mate* (they'd say to George)... the size, the shape, the gender didn't matter. We did have and lost a beautiful boy and you can never replace him". Leanne also commented that there is a higher instance of SIDS in boys. A fact that would probably not enter *other heads* but for Leanne and George was something that they were very conscious of. Echoing Leanne's sentiments of other parents a mother remarked **"My hope is for (a) a healthy child (b) not choose to have a boy but if that's what happens it happens"**.

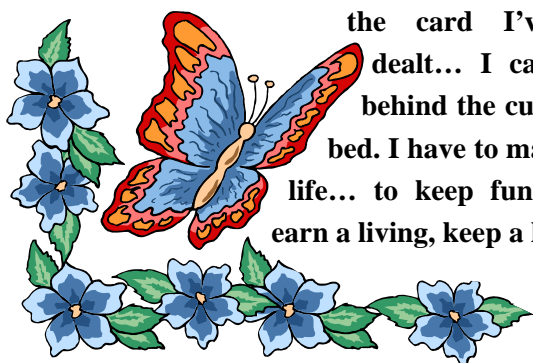
Leanne continued "even if you haven't lost a child you may wonder how other children will be in your family and how you will be with them". Several parents were able to relate with wondering whether they could ever love other children as much as they had loved their first child. However for those who had more than one child, when they had their *next* child they found there was more than enough love and concern for them.

In the early days of her grief Leanne recounted how she felt “terrified to go down the street and get a hair cut... people had known Alex as a happy, cute baby. Naturally they’d ask *how’s Alex?*” Leanne observed that she would have liked at this time to “have lived incognito”. Perhaps another change for families is becoming known as the ‘bereaved’ parents, an experience which is noted in this month’s Straight from the Heart contribution.

After a child has died a parent’s world and confidence in certainty and predictability of daily life are shattered. This was illustrated in Leanne’s comments “I was terrified that it will happen again... you can never say that the tragedy won’t happen again”. She added that the couple in the group who had had two children die were “testimony to that”. Speaking of their experiences one of the couple reflected **“at first there was a lot of support people around us. Then people freaked out, not again... there was nobody there... It was a very different experience.... What is there to say or do... there’s nothing.”** To this her partner said **“I was shell shocked. I didn’t want to talk to anybody”** and then **“there’s nothing to say you’re digging deeper and deeper to keep going”** was added by his wife. **“Because you change so much after you lose your child”**. A mother observed, **“you’re so very different... I grieve for my own self because I am not as great as who I was”**.

While views of self may change, the views or judgments that other people hold of *you* may change too. One of the parents shared a recent interaction with a friend which left her with a range of feelings and questions. She and her friend had watched the DVD played at her son’s funeral, **“I balled my eyes out”** she said. Her friend then commented *I don’t know how you’re doing it*. **“What else can I do. It’s**

the card I’ve been dealt... I can’t stay behind the curtains in bed. I have to maintain a life... to keep functioning, earn a living, keep a house”.



Leanne responded later that as a bereaved parent you **“can’t win because if you were on the other side of the curtain in bed they’d be at your door saying get up get going”**. **“People say I don’t know how I would’ve coped... I hear that as judging me”**. Comments of this sort, about coping and going on, make parents angry. **“How dare you... as if we were given a choice”** one parent responded. While another remarked **“It’s because I don’t look like a raving mess but they don’t know what goes on inside”**. A mother said **“I crashed for a year I let myself do that”**. Again “You cope ‘cause you have to” Leanne suggested and asked the mother “Do you ever say ‘What do you mean by that?’ (the coping comment!)”. In looking back at their path since their child had died some parents felt that the earlier days, the first three to six months were the **“hardest”**. Some people in that time had been **“abandoned”** by those who you’d hope would be understanding and sensitive. Sadly we heard there were **“the occasional rats and the temptation to be vindictive... I’ve got the sh... with him”**. Such feelings can be heightened if other people in the family make **“excuses for them”** or if people aren’t there when it really matters. The time has passed. We noted during the group’s time together that small children can be more supportive than adults. We were told about several incredibly perceptive comments made by a small child. He said that his little baby sister was not **“beeping anymore”** but also indicated that his parents and he **“were still here”**, still living but his **“teddy bears and trains are crying”**. As thoughts roamed around the changed self, sensitivities and patience levels were explored. Leanne shared one of the changes which she noticed happened to her following Alex’s death. She noted “I lost my tolerance, I no longer tolerate crap from people with trivia... do you realize what you are saying... that’s nothing in the scheme of things” she would wonder. Leanne also noted that “I trust my feelings now”. Linking with these a mother said **“I’m pissed off at minor things”**. Parents are also *irritated* about **“how vulnerable”** they could become **“in an instant”**. It was as if they were different people. We also heard from Leanne how early on with the raised sensitivity levels, reactions and emotions tended to be “blown up or bottled up”. However in

time she noted that “my coping mechanisms came back. I realized I can’t change them (people) I look and I say it’s sad but it’s nothing to do with me... I did not want anger at other people’s responses to mar Alex’s memory”.

Connecting with comments about emotions and reactions, several group members spoke of how they have felt that often it was hard to express or share intense feelings. Mostly parents had also become much more self aware and knew themselves better through their grieving. We listened to a mother’s recounting of an instance of her grief. Her emotions came up as **“whoosh over me... I said look out I’m going to cry... it’s a wave I couldn’t stop”**. She also recalled how after these emotions had been released she *regained her composure and kept going*.

The Continuing Journey: Meaning and Purpose

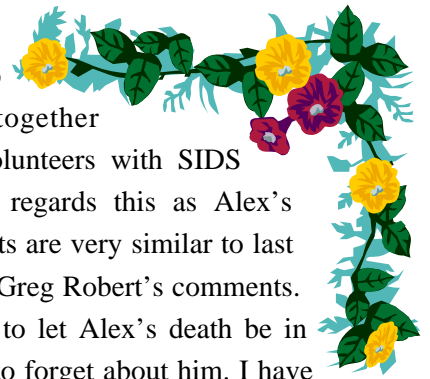
As the conversation continued to explore current worries and the *changed self* a parent reflected **“I always think the worst... I try the positive talk but I still can’t shake that feeling that something bad will happen. I’m angry that I have to live like that or rather I’m choosing that; I don’t know how not to... we are all in that boat. I could do anything I wanted to do, had goals, now I try to go with the flow and pretend to do that... but then the things they come and get me still four years on”**. Parents were approaching life more warily and with greater caution. Being cautious means protection **“I’ve learnt to prepare because you don’t know what is going to happen”** a group member said. Similar to this a parent commented that it had been striking to realise **“how little control you really have. We enjoy the simple things... we know that now”**. Perhaps that is an important legacy from their child’s life.

During the discussion Leanne was asked whether in her journey with grief was she ever **“stuck”** like this. This question came from a predicament expressed as **“I want to do something, I can’t do it, I can’t take a step”**. Leanne replied that while she hadn’t “exactly felt stuck” or been in the same position, she’d wanted “to really do things in Alex’s memory”. She “kept busy and had sort of pushed” so over time, she has

done scrap booking, put together photos and she volunteers with SIDS and Kids. Leanne regards this as Alex’s time. These thoughts are very similar to last month’s guest Mr. Greg Robert’s comments. **“My way was not to let Alex’s death be in vain or for people to forget about him. I have my own way of processing, of making sense of this... time for grief and the continuing journey”** Leanne reflected. Leanne noted that she allows herself “the permission to be sad, to be busy”. In the wake of their child’s death parents were mulling over all manner of thoughts, questions and plans. Taking chances or not, going on in the same direction or changing course. A mother observed **“either way it’s a risk... you are making the best of what’s available to you”**. A father spoke also about how before his child had died he’d been doing a training course and had nearly finished it but **“now I do what works... a course, I don’t know where I’m heading now (the course is) last thing I haven’t the space”**. A mother later extended her closely held conviction which she’d shared earlier by saying **“I want her life and death to make a difference... To me I knew I had to make sense and meaning to make it worth something... I had to push through and not sink”**. The search for meaning and purpose is a hard one. It can be lonely. In the midst of their grief parents found support in various ways **“to know that there are others in the same situation... that gets me through and that they have similar thoughts”** was important.

Questions, Concern, Control

When the evening’s discussion returned to the cause of the child’s death it was suggested that there can be some complicating issues for parents and how they are seen when their child died from a genetic condition. One parent observed she felt there was **“sort of stigma”** and the implication was **“what’s wrong with your DNA”**. Some questions asked by genetic counsellors had caused offence and felt hurtful. Although parents understood why they had been asked. With genetic conditions there are also particular implications for future pregnancies especially as for several couples the particular



diagnosis is not certain.

Through the evening several parents also spoke about how they now hate the expression *karma* and another group member remarked **“I hate the view of the world, it’s meant to be... God’s will etc”** a father said. One mother responded **“the truth is we don’t know”** and a mother said **“it’s neat until it happens to you”** and a father then concluded **“the theories don’t work”**. What became apparent to parents from their experiences with their children was **“how little control you really have”** and how in many situations involving children and their health there is **“the lack of control”** and a sense of having **“no power”**.

At the start of her grief journey Leanne did “a lot of spiritual searching”. Such searching has been mentioned very often by parents who are bereaved. Leanne also found meditation “helpful and of comfort”.

One of the questions that was put to Leanne was *how did she sleep at night when her other children were born*. Leanne explained initially she had an apnea monitor when Laura was a baby and “would watch the light at night and poke and prod at her to check on her”. From her experiences when her other children are ill or have had accidents, Leanne has concluded “you are anxious with kids... you’ve had such a tragic loss that this condition brings it back”. Similar to this a group member shared **“it (her child being unwell) freaked me out... I really panic”**. Leanne feels that over the years her worry has “lessened” with the arrival of her other two daughters. However she commented “it’s still there”. Responding to this a father said he and his wife become very concerned if their son is sick and he expressed some relief that others felt this way too. Although his wife, with her tongue in cheek, replied **“no that’s just us”**. In hospital settings some parents in the May group had felt that at times they were not given the reassurance from staff they needed as bereaved parents. A word or acknowledgement would have been supportive. It could have reduced fears. In supporting other people who are bereaved a mother said sometimes it’s helpful to give **“not flowers but pen and paper”**.

Towards the end of the evening a mother from her daughter’s lifetime observed **“life and death are the same things. They go together. If you want to celebrate her life you have to celebrate her death”**. She had made a book about her daughter’s life from her daughter’s perspective using her daughter’s words. **“I felt close to her when doing it and sad when it was finished... it’s the connection”**. This was a precious gift to others in her family.

Feelings of closeness with the loved child who has died come in all different ways. We heard about dreams in which the dreamer had felt a baby touch their heart. **“In my dream... it freaked me out, the skeptical me but it was also somehow comforting”**. A number of parents felt disappointed when their child had not returned to them in dreams. Parents in the May group had also seen how in life there can be **“weird and totally bizarre experiences”**. **“I use to be scared of the sounds of the night, not now I listen I want it to happen”** a mother remarked. Parents continued to recall and share experiences where they had felt there were signs, **“it’s awesome the signs that make us feel good... the meaning that we get out of things”**. Being able to share experiences such as this with others who are understanding and respectful is one of the great strengths of the PBSG.

“I allow her to effect and direct my life still I wonder where are you come and see me”.

It was wonderful to have Leanne as our May guest. We are very grateful for the experiences that she shared and her generous and honest responses. And for those who could stay as always happens there was more conversation and connection over supper.



Straight from the Heart

We would like to thank Ms. Jan Mitchell, Casey Munro's mother, for sending us her response to the themes of the April Newsletter. The moving insights and very telling family experiences which Jan recounts will ring true for many families who are grieving.

*In loving memory of
Casey Munro
10.12.1984 – 01.04.2000*

I am sitting (at...) and needed to respond to the April newsletter as many valid and true points were raised.

My daughter Casey Munro died on 1st April 2000 after a diagnosed 2 week battle with leukemia (ALL) Casey was aged 15 years, eight years on at times it is still very hard to come to grips with but I have learned to live and manage in my own way. Living in a small community EVERYONE knew when Case died, even before we got home from RCH, her funeral was huge over 700 people attended - it is mainly a blur for me!!

I remember the first time I went into the local supermarket (only one in town) the whole place went quiet and people just stared, all I wanted to do was scream - I have to live, eat & drink, as people just do not know what to say!! I also worked at the local hospital which at times was hard as patients would say so you're Jan Munro whose daughter died - then expect a detailed answer I would say - yes that is right and I am Ryan's mum!!! Also small communities will rally together which they did for me, my son Ryan who was 13 at the time and my ex-husband.

One of the hardest things is that people do forget, my husband Peter had a person hassle him re shave hair day and sponsoring them and they were very persistent, Peter pointed out that his stepdaughter Casey died 8 years ago and that we support all facets of fundraising for all cancer, this person backed off apologised profusely stating they had forgotten!!!!

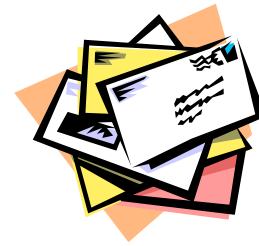
The other point I found very true is that we shouldn't beat ourselves up if we can and start to travel well - we do have a right to "travel well", it doesn't mean our child is forgotten, just we have learned to deal with our grief in our own way and should not feel guilty.

Since Casey's death life has certainly had its ups and downs. I remarried 5 years ago, Peter was already my partner when Case died and it certainly affected him as Case and Peter got on like a house on fire. We have more grief with the sudden passing of my mum in 2005, my dad 2007 and Peter's mum also in 2007, we both feel quite experienced at this!!!!!! But we are surviving and we do "travel well" but never forget.

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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*Our letter box needs
filling up!*

Or email Jane on: jane.sullivan@rch.org.au

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

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

Our guest for the evening will be Ms. Jenny Robinson, a bereaved parent and parent supporter. Jenny will guide a discussion on the experiences and needs of sisters and brothers who are grieving through the theme: *'When's Samuel coming back?: A sister's journey of grief from childhood to adolescence.'*

Please join us for the June group.

The newsletter is always a team effort. Thank you to Ms. Leanne Fink, the parents of the Parents' Bereavement Support Group, Carol Quayle, Vivienne Bateman and to our skilled, committed Administration Team- Carly Burnett, Rebecca Welsh and Sam Harris for their work with the newsletter.



Jane Sullivan
Author & Editor