

# FAMILY BEREAVEMENT SUPPORT PROGRAMME



Social Work Department  
Royal Children's Hospital

NEWSLETTER NOVEMBER 2008

A very warm welcome to the November newsletter of the Family Bereavement Support Programme. Through reading the newsletters and being a part of the groups we hope that you will find connections with others, support, encouragement and information to help sustain you as you grieve for and love your child.

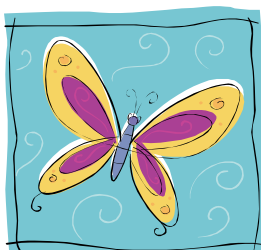
## I'm Different Now: my changed identity since my child died

The parents who joined together for the November PBSG were greeted and warmly welcomed.

The experiences with their child which had led parents to the group and the challenges of returning to the Hospital to be a part of the Parent Bereavement Support Group were acknowledged. For some parents in the group it had been two brief months since their child had died while for others it was several years since grief had entered their lives. No matter how long parents had been grieving and appreciating the uniqueness of each family story, there was a shared bond between parents. As became clearer during the night there is also a particular sense of understanding and camaraderie. We were to hear during the night when parents spoke about their greatly loved and missed child that many changes, learnings and reworking of life plans had happened from the time of diagnosis with a life altering condition and since their death.

As happens, introductions and conversation amongst parents and with the little social work team had begun before the group was *formally underway*. However as several parents were coming to the group for the first time and as is the pattern of the evening we spent a few

moments in introducing the group. This introduction may also be helpful for those who don't come to the group. The PBSG is a place where parents are able to *bring and share their child* in an open forum. A place



not to be judged or stopped as often happens in the community when parents talk about a child who has died. In the group parents can share with others what they feel comfortable with and are able to speak about. The group can also be a time and space to be quiet, to listen and reflect. The group offers an opportunity to be connected with other parents who are grieving and to find ways together of living with the loss of a child. The discussion can be very moving and may touch parents deeply. If through the night parents feel somewhat overwhelmed by the conversation they may need to take some time out from the group. Carol or Jane are able to be with parents through this time. We mentioned too in introducing the group that Jane takes notes for the newsletter. The newsletter is a resource for families who come to the group, those who don't and for family, friends and health professionals who support grieving parents. Vivienne (Bateman, Bereavement Services Co-ordinator) and Jane are available to meet with parents who attend the group or who read the newsletters if there are matters that they would like to talk over more privately. Viv and Jane can be reached through the Social Work Department on (03) 9345 6111.

### ***Beginnings-***

It was a great pleasure to be able to have at the November Group our Bereavement Services Co-ordinator, Ms. Vivienne Bateman. Viv is known to many parents who are grieving through her work in the Hospital and over many years in community organisations. Viv who has been a guest at a previous PBSG also contributes to the

newsletter updates about bereavement care in the Hospital and to RCH's policy and service developments. She welcomes hearing from parents about their experiences and suggestions to improve the Hospital support of grieving families. Viv's role in the Hospital also includes staff education and support.

Viv began by saying a few words around the topic for the evening. These helped to set the context for the conversation. "The death of a child" Viv said "is a life changing event. The bereaved parents I've met have often said that they are changed by this experience and they aren't the same person that they were before the child's death... The changes are many and have different dimensions. Tonight's topic is focusing on how the death of your child has changed you, your identity, your relationships and the way you look at the world." Viv then added "we need not stay on the topic but through the night we will be coming back to it. This group provides an opportunity to talk and there are not too many other spaces where parents can talk about their child or can talk with other bereaved parents".

Before moving further into discussion of this topic Viv spoke a little about her background. Viv worked at SIDS and Kids for eleven years. She has spent time with hundreds of families whose children have died through many different causes. She has also worked at the Road Trauma Support Team and supported those who have experienced the death of a family member who has died as a result of a motor vehicle accident. With these words Viv also reassured parents of the safety of the group process and that she would "not take you where you don't want to go".

***Every part of me- All sorts of change***

"A child's death is usually the most significant bereavement a parent will ever experience in their life" Viv observed. Through the evening Viv highlighted the fact that a child's death is very different from other griefs that parents may have experienced. Parents who attended this group had experienced the death of partners and of grandparents and parents and it was agreed that the lived experience of a child's death results in a unique grief. Viv explored with the group the way a child's death was different. This comes from being out of step with the

natural, expected order of life and at loggerheads with the parent's role as protector, defender and carer. A mother reflected "**there's a need to be able to protect (your child) ... I feel responsible**". Viv noted how parents "will often comment about how they look at the world differently and how there are all sorts of changes and struggles". Holding this in mind Viv asked parents about the types of changes and struggles they were currently encountering. A parent in the group who was more recently bereaved commented "**I'm not good. I'm trying; I do things for him; I try to bring some normality in for the other kids... there are good days... ups and downs.**" To these words, another parent who has been grieving for a slightly longer time, added "**it's gotten harder. As opposed to the first few months when I was in work mode. Lots to do with the funeral. I don't know how I did it, all the things. Friends think I should be better. They are shocked to hear that it's worst**". A parent later said how after the first year since her child has died "**It's a turning point for me there are no more firsts**". This brought a slight sense of relief. These experiences highlighted and reminded us, that grieving is an on-going experience rather than a time limited *episode*. Other people, though, often expect a parent's grief has gone away. "**It doesn't come up or I don't want to talk about it**" one parent remarked. Because, talking about a child's death and a parent's suffering seems on some days that it's just too hard, too hard for everyone. As Viv commented they (friends and extended family) may be in a "different space to that of a grieving parent. The lives and worlds of people who are bereaved and those who are not are very different.

Extending earlier thoughts about *doing things*, a mother talked about the difficulties that she had in doing tasks that she once had done. Mindful that very often people who are grieving find that they have trouble with thinking and planning, Viv asked about how the parent was *finding* her concentration. The mother said she didn't have "**the (same) level of energy**" to concentrate. Lack of energy and feelings of exhaustion were some of the experiences that rang through the November group. Reflected in these words "**It's hard to get motivated**". "**I can be in my pyjamas until ten thirty... I'm forced to get out there... It's never not in your mind, you can put it back but it's always there**". Connecting further with comments about energy and exhaustion, we heard how often parents really pushed themselves to do things. One example mentioned by a mother in the group was visiting the child care centre her son had attended. There is a feeling of wanting to do this and how important it is but it is just plain hard- "**he**

**should be there that's all**". Sometimes energy had been so diminished that grieving parents had found that prescription medication had a role in increasing energy. A parent spoke of how, with the support and monitoring of a GP, medication was having a positive effect for her. It had made a real difference to what the mother could do. Several parents told the group that they were now managing only two to three days of paid work. Over supper a father spoke about how he too had changed his work situation and how a less stressful and demanding job was good for him at this time. A change in hours at work was a helpful strategy for a number of group members. Work seemed for some parents in the November group (and previous groups) to take a lesser priority than before the child had died. Thoughts around priority led a parent to say **"I'm not prepared to have a less than good life now. I want good relationships around me... I'm determined to have that life... (her daughter's name) didn't have a choice"**. From discussions, it seems that some changes occur in relation to priorities and to the parents' philosophy of life.

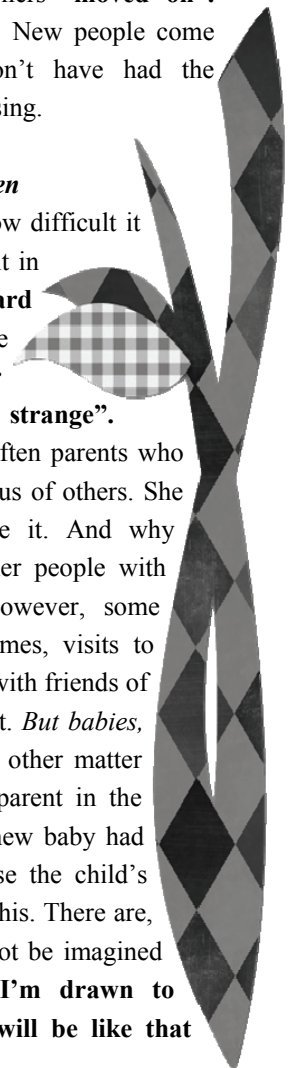
Some other changes that parents had gone through as we heard and saw are visual and constant, such as hair changing or more permanent visual changes for example having tattoos. There are changes to so many aspects of life. Relationships are altered through grief **"Every single relationship with friends and family have all changed"**. **"Communication is not there and that is the key."** A father summarized about how relationships can endure the challenge of grief. It was heartening to learn that some extended families were providing wonderful support to parents and **"mentioned his (the child's) name all the time"**. Sadly though, other people were struggling with how to *understand* parents. **"I find it exhausting saying my daughter died and having to deal with people's reactions. You end up comforting them. You take a deep breath you put on a mask... it's all rosy"**. Joining with these thoughts another group member said **"people don't know how to react, they think if they talk about it it will upset me. I could talk all day about her. I'm going to be (upset) anyway it's not a bad thing to cry. With some you don't go into detail"**. Other people's lack of understanding and sometimes insensitivities meant for parents that it was **"too hard (to explain), I don't have the time... I just get on with it... It makes me angry... it eats me up but it troubles me more than him"**. Her partner added in response **"as long as (his partner and he) are safe that's all that matters. Sometimes I'm the mess and I'm all caught up with me and she's stronger. The longer it goes on the more you have to find each other"**. As well as with communication with family and friends, the

importance of communication between a grieving couple was mentioned in the November group as it has been in earlier groups. During the evening's conversation we acknowledged that in addition to talking about how things are within a couple it is important to think about the timing of that talk. Some times may be better than other times. For example, if a parent has been drinking or has *closed down* and gone silent, maybe that's not the moment to raise concerns about particular behaviours. A time when the behaviour isn't happening may meet with a better reception. It was felt that a clear head may be needed to take in another's concerns and not feel criticized. The earlier comments about crying and individual differences resonated with a father's comments about how he has tears **"in front of the TV"**. Tears flow at all sorts of times and places. As the conversation continued in response to Viv's initial question (the way you've changed) a father shared that over time while he has **"an expectation that certain days will be hard"** there are others that **"you can't see (the challenges) coming"**. It seems, a father concluded from his experiences, that **"people just forget"**. He also shared with the group the complexities of losing some particular connections through others to his daughter. For example over time her school mates and teachers **"moved on"**. There's less of a community memory. New people come into his family's life and they won't have had the opportunity to know her. This is distressing.

#### *A Heart Divided: other people's children*

During the night parents shared just how difficult it often is for them to see, hold or delight in new babies. A father observed **"it's hard to be around other children (in the extended family)... with another child... I just can't describe it, it's strange"**.

Vivienne shared with the group how often parents who are grieving can feel jealous and envious of others. She continued and said "it's ok to name it. And why wouldn't it be hard to be around other people with babies, being happy". In contrast however, some parents in the group found that at times, visits to schools and birthday parties and parks with friends of the same age of the children were great. *But babies*, for some parents, seem to be a whole other matter and just too hard to deal with. One parent in the group explained how for her when a new baby had come into her circle she could not use the child's name. Although she felt terrible about this. There are, it seems, changes in grief that could not be imagined until "you're right in that place". **"I'm drawn to younger kids... I don't know if it will be like that"**



**forever. I don't have the tolerance... They don't know how to handle me. I don't know how to handle me and what we've lost.**" Yet, as a group member said, **"kids say what they think"**. Their honesty and tackling of the big questions can be refreshing. From parents' comments we learnt that if another child in the family looks like the child who has died, it can feel like both a gift and a burden. Once it may have been good and fun but after a child has died it seems like a painful reminder of loss.

#### *What Now?- New Directions*

An added dimension to the feelings and changes that may be experienced, Viv continued, can also be if parents don't have other children if an only child has died. As a mother pointed out **"times and routines don't matter now"**. Another mother said **"it's a huge change. Suddenly your life revolves around you. Once you wanted a minute to yourself and now you feel guilty to feel that"**. For some, including one father in the group, the space had been filled

by **"work, work, work. That's coming to a halt, my motivations waning. I've been a bit off of late. Initially I was up and off"**. The void left in a parents life was expressed in this way **"Twenty-four hours to fill some how. She was our whole life, my world revolved around**

**her"**. As parents shared their experience of change one of the most significant was finding something *as* worthwhile and time consuming as caring for their child. Not surprisingly nothing had the same joy or meaning. Nothing compared to being a parent. Activities and tasks still related to the child (such as visiting the cemetery) gave some experience of role and satisfaction. But they are not the same.

Continuing thoughts about changes, a mother said **"I've changed a lot... I didn't think a lot about myself before, visually I've changed, lost weight, I look after me... I've had the emptiness and grief... I gave myself a year to grieve"**. The mother emphasized her grief hadn't ended but rather seemed to have been transformed. In commenting on her journey with grief over that time and linking with our introductory thoughts she said **"there's nowhere else (except in the PBSG) I feel the comfort"**.

#### *Faith Lost: Faith Found- grief and beliefs*

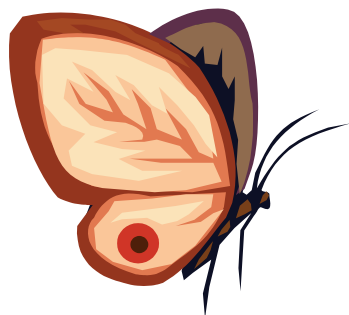
One of the most profound changes that parents who are bereaved have experienced is to their faith. Viv described how a child's death can challenge faith. She noted again

that people vary in how they respond. She said "some people question their faith while other's faith becomes stronger". Viv asked parents about their experience. In thinking about this consequence of grief a father said **"my family, are strong Catholics. We went to church every week (now)... sometimes I go weddings"**. He continued by explaining that when his child was born he felt (he lost his faith in God) **"I just stayed away (from church) I don't go... I don't force my opinion on everyone else... there's no need, I don't feel the need. My faith just waned not at the death but at birth"**. Highlighting individual differences, in contrast, a mother said how her faith was **"a bit more... you have to believe in something"**. Another father then shared his experience of faith **"Yes and no, since (his child's name who had died) we go every Saturday to church"**. A mother expressed her thoughts about faith to the group with these words: **"Does it help? I'm needing to have something I can trust in... I feel better trusting and hope that he is looked after the way we looked after him... I don't like God anymore. I pray to Mary and I never had before that... The baby is somewhere. His soul is being looked after"**. Her partner added **"I believe in something... it's something to make us strong. To believe that he is at rest"**. For some parents, thoughts about their child being in a safe and healing place brought a comfort. **"Hopefully she's there... running and dancing... causing trouble"**. Another comfort and encouragement for several parents in the group was feeling the closeness of their child, being with them. Parents often had a very strong sense that their child is with them. **"She's with me everywhere I feel her here (pointing to her heart). I don't need a place to go to. I talk to her when I feel that she is not as close I talk... I dream about her. It gives me faith she's with me. I feel the strength"**. Some parents thought of their child now *as being* **"the brightest star in the sky"**.

As thoughts about belief continued Viv spoke about dreams. In dreams, Viv said, grieving parents sometimes find their children appear to their parents saying *I'm ok mummy*. Viv wondered whether the parents in the group had any sense of this. To this a father said **"I ache for it... I'm waiting for it... I envy people who've had it... I'm hanging out for it"**. From a different stance a mother described that she did not really want to have such a dream because **"I want her with me, I don't want to let her go"**.

#### *Little and Large Legacies- some good amongst the loss*

**"(I'd) like some of her qualities... I was so lucky to have her... (they) are gifts"**.



As the conversation continued Vivienne asked parents whether “out of all the devastation and change there had been any changes for the better”. A father said **“I try to be positive. It started when she was born there were hurdles. I try to be happy and focus on the positive... I relax a bit more, I’m not as worked up”**. Vivienne wondered whether for this father some things “now go through to the keeper”? He agreed and a mother extended this comment by saying **“work doesn’t seem to get to me as much as it did previously”**. Another mother shared her thoughts: **“I’m better off because of him, of having had him, his life rather than his death has enriched me. To have not had him... I couldn’t imagine my life without knowing him. His legacy is to help others it’s a good thing. I couldn’t have done that without him”**. Such legacies and parental resolutions to do good things in tribute to their child are woven in these words **“I want to use the experience of (her daughter’s name) life and death to have a more meaningful life. It serves me well”**. She gave some examples of how this quality and outlook was being used constructively to help others. In response, Viv commented on the strength that she had noted in the mother’s words and presence. To this the mother reflected on not so much her strength as her **“ferociousness”**. While however, another father in the group said **“I couldn’t really say really”** about changes for the better. Viv acknowledged that for some parents at the “moment it’s all a bit new. With the passage of time you may be able to relate to it but at two months, not” Viv said. Finding a small fragment of good *may* only come after time, experience and looking back.

From being with those who have experienced the death of a child, Viv has seen also how often parents are more “compassionate to others. There’s a particular “knowing”. Tragedies change us in ways that are not learnt, not taught. It doesn’t come early on in time but often people become very supportive to others. The memory of their child is kept alive by supporting others... Regardless of the age of the child. You can’t put a finger on it but there is a richness to the personalities that have come out of this awful, dreadful experience” Viv reflected.

### ***Always With Us***

As we moved towards the end of the evening Viv and the group spoke about what parents did in memory of their child, “apart from coming here”. On the subject of protecting and strengthening of the child’s memory and of keeping them close, parents had lots of ideas.

These included:

blowing bubbles

framing portraits

playing guitar

visiting the cemetery

lighting candles

singing songs we used to sing together

creating gardens

keeping their child's ashes on toy boxes in the house or in lockets near the heart

creating books for people to write their thoughts about their child in

kissing partners once for themselves and once for their child who had died each morning

And taking their child symbolically with them to work

**“He gives me a hand, you’re coming to work to give me a hand, we can do harder things now cause we are stronger”**. Some children are “collected” on the way to work and parents talk to them about the day ahead at work.



And some of the other things that keep the child close include:

having personalised number plates for cars

bracelets with initials and names

Listening to music of all sorts not just kids **“still listen to that, reminds me of the good times”**,

Photos

having items of clothing and boots nearby or moving them to be close and a part of the action!

Most parents continued to talk easily and naturally to their children and that was as it always had been a great joy.

Through the evening Viv read some quotations from parents that had come from the book ‘Always Your Child’ (2000 produced by SIDS and Kids). These eloquently illustrated the evening’s themes.

*‘When Julian was born we embraced a life on an emotional rollercoaster of which one day was never even similar to the next. It was a life of chaos, beautiful chaos, not even similar to anyone else we knew, but we loved this life... We were thankful for what it gave to our other children... this was our purpose. I was so proud of Julian. He spoke through his lack of words and his inability to walk, and the understanding and patience he demanded of others. Then so suddenly he died. The pain was so great. The thought of the emptiness from the minute we woke until we slept was*

*unthinkable. From that day on life would once again change and a bitter calm filled the air and we knew that life would now be easier but never ever better. I felt that we had lost what made us special, privileged and unique' (Therese)*

*'All my priorities were re-ordered. For the first time for ages it was the real things that counted. What mattered to us was the loss of our child and all the implications that had. I remember going back to work and doing that too quickly and how trifling most things were. You know, people bitching and whingeing about normal things at work, which to me were totally insignificant, and so it resets your priorities totally. You don't care about any of that. You put on a façade - you go through the emotions but it really does alter your priorities for a considerable amount of time. You are off to the side from everyone else for ages. But eventually you're dragged back into the normal realm of things...' (Peter)*

At the end of this part of the evening Viv observed "A child's death is a life changing event. I have noticed that parents will always speak about their child with pride... it is almost palpable. It was evident tonight, your faces lightened as you spoke about your children. And the others here understand, not entirely but others here were nodding, agreeing really knowing". Viv concluded her 'formal time' with the group by saying that it had been "a privilege" to be with the group, thanked the parents for all that they had shared and wished them well.

Our sincere thanks to Viv for being with the group. We are truly grateful for reflections she shared, for all her care and for supporting the conversation as it unfolded in such an encouraging way. And as always happens, more of the conversation continued over supper.

#### ***A glimpse into the November Recently Bereaved Parents' Evening.***

A very, very small group of parents met early in November. The conversation focused mostly on the immediate and enormous impact of a child's death and how this has been lived with. Activity, personal and formal support counselling and groups all had a part to play.

Linking with the November PBSG the conversation also explored the journey to find a worthwhile purpose and new meaning in life after a beloved child has died. Important messages from the conversation were to try out different ways and to follow the path that seems right and supportive. Knowing this path can change was also a valuable learning.

*This exert from The Little Prince and the quotation from Helen Keller seemed to give further expression and analogy to some of what parents had spoken of the November groups. We have included them for reflection.*

#### ***The Little Prince Antoine de Saint Exupère, 1943***

"And at night you will look up at the stars. Where I live everything is so small that I cannot show you where my star is to be found. It is better, like that. My star will just be one of the stars, for you. And so you will love to watch all the stars in the heavens... they will all be your friends. And, besides, I am going to make you a present..."

He laughed again.

"Ah, little prince, dear little prince! I love to hear that laughter!"

"That is my present. Just that. It will be as it was when we drank the water..."

"What are you trying to say?"

"All men have the stars," he answered, "but they are not the same things for different people. For some, who are travellers, the stars are guides. For others they are no more than little lights in the sky.

For others, who are scholars, they are problems. For my businessman they are wealth. But all these stars are silent. You --you alone--will have the stars as no one else has them--"

"What are you trying to say?"

"In one of the stars I shall be living. In one of them I shall be laughing. And so it will be as if all the stars were laughing, when you look at the sky at night... You--only you--will have stars that can laugh!"

And he laughed again.

"And when your sorrow is comforted (time soothes all sorrow) you will be content that you have known me. You will always be my friend. You will want to laugh with me. And you will sometimes open your window, so, for that pleasure... And your friends will be properly astonished to see you laughing as you look up at the sky! Then you will say to them, 'Yes, the stars always make me laugh!' And they will think you are crazy. It will be a very shabby trick that I shall have played on you..."

And he laughed again.

"It will be as if, in place of the stars, I had given you a great number of little bells that knew how to laugh..."

And he laughed again.

*"Death is no more than passing from one room into another. But there's a difference for me, you know. Because in that other room I shall be able to see."*

Helen Keller

# *Straight from the Heart*

**In cherished remembrance of  
Olivia Alexandra Tait  
08/03/1994 – 12/04/05**

*We are privileged to be able to include this poem entitled Changes. The piece contemplates how in grief the passage of time brings particular changes. The sense of distance and separation is contrasted with a hope for reunion.*

*We feel those who read Changes will know the anguish, love and transition it describes and be moved by its sentiment.*

*Thankyou, Olivia's Dad.*

## *Changes*

The time since we last saw you is measured now in years  
And it saddens me to think how much has changed  
Where once we measured weeks and days, each one marked by tears  
I reflect on how our life is rearranged

The evidence of your time with us has now begun to fade  
The things you touched are gone or getting old  
I'm shocked to see how time has changed the places where you played  
The links to your short time on earth are becoming hard to hold

The trees we planted in the yard have grown up strong and tall  
You should see how big they've come to be  
At last the courtyard's finished, there are roses on the wall  
I'd love to show you what we've done, I'd be proud for you to see

Then we meet acquaintances who can't share our regret  
They missed the joy of knowing who you were  
And even those who knew you are beginning to forget  
As time goes by the details start to blur

But with every second breath  
I see your untimely death  
Has changed the very fabric of the earth

And if others choose to act  
As though your life was not a fact  
I'll recollect your face for all it's worth

Each time life takes a turn I see the gap between us grow  
Each change of season pushes you from sight  
But in truth they bring us closer to the day we'll come to know  
How our different paths converging will make everything seem right

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.

*At this time we would especially welcome pieces about moving through the festive season and into the new year*

Please forward them to:

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



*Our letter box is waiting!*

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

**Thursday 11th December**

7:30 pm – 9:30 pm

Seminar Room 2, 4th Floor

Front Entry Building

Royal Children's Hospital

The December group will be joined by Ms. Evelyn Heard (Chaplain RCH) in **Snowflakes in the Desert: the unexpected journey of grieving through the festive season and into another year.**

Ev will guide a conversation about the particular challenges and concerns that families who are bereaved may face at this time of the year. During the evening there will be an opportunity for parents to *create a snowflake* as a symbol of remembrance and love for their child.

**Please note the December Group meets in the second week of the month.**

We look forward to being with you at the December group for an evening of conversation and symbol making.

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



Jane Sullivan  
Author & Editor