

PARENTS' BEREAVEMENT SUPPORT GROUP



Social Work Department
Royal Children's Hospital

JUNE 2005 NEWSLETTER

Welcome to the June newsletter of the Family Bereavement Support Programme. We hope that the newsletters and groups can be a source of support, encouragement and connection with others to help nurture you as you grieve for your child.

Our Children in Our Words: What Bereaved Parents are Talking and Thinking About.

We warmly welcomed parents who came together on another very cold Melbourne night. As we began the evening's group, we acknowledged parents who were joining the group for the first time, those who had been a part of previous groups, parents whose child's death, is more recent and others who have been living with loss for some time. No matter the time since a child's death or what brought an end to their life, it seems from what parents have said that there is a strong bond and sense of understanding amongst those who grieve. We hope the Parents' Bereavement Support Group enables this unique support to be experienced.

We spent a moment longer talking about the group. The group aims to be a safe, respectful place where stories can be shared, acknowledged and ways of living with grief explored. Notes are taken to form the newsletter. Sometimes during a group, matters can be touched upon that parents may want to *pursue* away from the group with a trusted family member, friend or support person. Carol and Jane are available in between groups to talk privately with parents.

This evening's group was a little different from the usual pattern of the monthly groups. We did not have a guest speaker. Rather it was an op-

portunity for parents to *share* their child with other parents and to begin with what was foremost in their hearts and minds. Parents had been asked if they felt able to bring a photograph, symbol or memento of their child to show other group members.

By way of brief introduction, Carol read the first part of a meditation from *A Time To Grieve: meditations for healing after the death of a loved one* by Carol Staudacher (1994).

Love Hurts

From love one can only escape at the price of life itself; and no lessening of sorrow is worth exile from that stream of all things human and divine. Freya Stark

Sometimes love hurts. And it hurts most when we are surviving the death of someone we love. It is at such a time that we look at ourselves and wonder what possesses us to love as strongly and as deeply as we do. Why can't we, we may wonder, love like other people seem to? Love and keep protected. Love ourselves to the exclusion of others. Love without having it affect the rest of our lives. But such loves are not the kind of love we would truly value or benefit from. So we have to resign ourselves to being capable of love that hurts. To be otherwise would be to



withdraw from life, to exist in a sort of emotional exile, not benefiting from or feeling all the joys of the human experience. Our love may be especially hurtful with our loved one gone, but the fact of that love is a gift.

Once the meditation had been read group members were encouraged to *take the conversation where they wanted to*. This proved to be a little harder than anticipated! It can be very difficult to be the first voice in the room; to know where to start and what to say about a child so greatly loved and such life altering times. In supporting parents to talk about their experience we noted the sense of courage it can take to come to a bereavement support group. *Once voices were found*, words (including a few colourful ones!), tears and even laughter flowed.

A father who is more familiar with the group began the conversation. He told us about his baby son who had been diagnosed with a genetic life shortening condition, almost two years ago. His son had died eighteen months ago at almost five months of age. With the nature of the condition there had been what his father was later to call **“pre grieving”** (before his son’s death). Mirroring these comments another member of the group remarked **“You grieve on all levels, every milestone that you didn’t make, the sitting, the walking, all of what’s meant to happen”**.

The mother of the baby boy had returned to work twelve months after his death. Her work brings her into contact with parents who have children with disabilities. Their stories touch her. She has a particular empathy and understanding for parents. There are times when their comments and perceptions can give her particular cause to contrast her experiences. She illustrated this through the example of knowing a child’s diagnosis is not always helpful not if means you know *how it will all end*, **“I’d rather never had known”**. While another mother whose child had not during her life or after her death been given a definite diagnosis summarized her situation in this way: **“One in four means one in four times every time you conceive. If you don’t have a diagnosis, or if you do it’s still one in four”**. **What would you do if there was a prenatal test? Would that be it?** Several families faced this incredible dilemma. One mother reflected the

complexity of this by saying **“if I ended a pregnancy, wouldn’t it be dishonouring (her child’s) life”**. ...**I’d give my whole body if my child could live”**.

“At diagnosis, that’s when your life changes” observed another group member. She contributed **“so what if there is an eighty per cent chance of survival, ...if your child is in the twenty per cent who dies what’s the point?”** One mother in speaking about the diagnosis of her daughter remarked that it was very hard to **“sink in”**. She has also confronted the disbelief and arguments of family members who questioned **“are you sure, they must be wrong... now she’s the oncologist”**. It can be exasperating for parents to have to argue against those who have become *self appointed medical experts* and challenge what parents have been told. The memories of the time of diagnosis would later lead a mother whose daughter had died seven weeks ago to comment how that process had been **“surreal”**. She was told her daughter would *die at six months*. With each month that went by **“I’d passed that point and thought she’ll keep going”**.... **It can be staggering that in the year 2005 how can they not cure something, you assume there is an easy answer for everything. You don’t plan on your kids going first”**. The death of a child was described by a father as being **“unnatural”**. While another parent responded **“they are not supposed to die;** a view seconded by all parents. These parents’ voices were joined by a mother whose child died twenty two months ago. His birthday falls on the weekend following this group and his mother reflected **“it’s so hard when they’re not with you, but I wouldn’t have changed it for the world... what he gave to our family, it’s incredible... I needed to be here because of his birthday”**. Thinking back to her early times of coming to the group, she reflected that it can be **“awful to start to speak”** but talked too about the sense of kindred spirits she had met within the group. She commented on how she has found it is *important to take from the stories* of other parents **“only what you need to”** and not to be overwhelmed by the **“sadness”**.

“I haven’t cried until now”. With these words a mother began to introduce herself and her daughter. During the evening she was to recall her experiences and the seven weeks since her daugh-

ter's death, she wept and wept. While a mother sitting by her and offering her tissues said **"I can't cry.... I'm scared if I cry... what will happen?"** A question asked by many parents who are grieving. (We should of course remember that tears aren't *mandatory* in grief or in the group. However, in the group we have a big supply of tissues for when they are needed). In responding to the mother who had said she could not cry another said **"it doesn't matter when it comes, let it come, I had to forget about what people think about me, I need to be me"**. Her guidance was **"cry where you trust being"**.

At a later time in the evening we heard that some members of the group thought of tears as a **"weakness"**. We wondered where this message had come from?

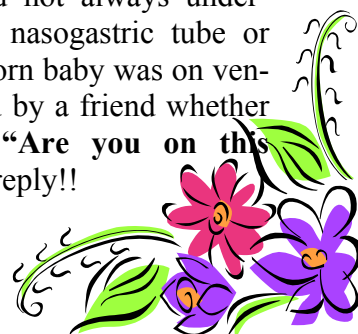
A mother who joined the group for the first time introduced us to her daughter. Her daughter was ten when she had died from a brain tumour in the early part of the new year; a tumour which she had battled against for a number of years. Her mother recollected the years of treatment following her daughter's diagnosis. She spoke about the feelings surrounding her illness and death as being **"unbelievable, it's hard, people don't really understand"**. These experiences had brought her to this evening's group. The mother held the hope that other parents who are grieving would have a greater understanding of how life is for her now. She observed **"I don't know how I'm going.... you can understand but you can't understand"**. Grief was summed up by one father; **"it's a real hard slog"**. As the conversation moved around the group, another mother talked about the circumstance of her daughter's sudden death at the age of three. Her death, she reflected, was different from those described by other parents. It had been **"totally unexpected"**. Her daughter had a rare condition which presented certain **"structural"** problems. Her daughter needed particular support with eating and her airways, yet she was otherwise very healthy and fit. As her mother said **"she was just brilliant, she touched people, an influence on so many people, once (daughter's name) engaged that was it... her legacy is extraordinary"**. The mother described how her daughter's vibrant personality had drawn the normally **"reserved"** parent into a more *social world*. The mother went on to say that family, friends and the local community had been extremely suppor-

tive of the family. Many parents who are grieving find that there are many marvelous people around. Although as we heard through the conversation not all people are understanding of a family's grief.

Parents during the evening spoke about the physical and emotional difficulties which their children had to endure because of the medical conditions or disabilities they had. Painful procedures or routine tests which held no benefit and only took precious time away from being at home had challenged parents with questions of **"quality of life"**. **Why and what for?** became key questions as parents tried to protect their child from unnecessary pain. For several parents there was a glimmer of relief that now for their child there was **"no more suffering"**. However, understandably, grappled with *why they had to be so ill or have such a hard time in the first place*.

"The rollercoaster gets better, but it really never gets better". The particular care needs of their children meant that a number of parents in the group knew the rigours of nasogastric tube feeding, gastrostomies and tracheostomies. Summed up by one parent in this way **"Being fed by a tube ...doesn't that suck"**.

Amongst some of these parents, there were mothers who knew the arduous process of expressing breast milk **"I was determined"** said one mother. A father whose child had a NG tube explained how helping with tube changes and feeding was **"... a task, one thing I could contribute"**. While his partner said **"I'd go out (during tube changes) and cry. That was my support"**. We heard stories of NG feeding in *Macca's*, and in pubs. **"How many people have had that experience?"** asked a father. From parents' comments it seemed that having *a tube* in for some gave the *message* to other people that their child had particular needs. On occasions this helped to ward off questions about *unreached developmental milestones* and prevented *rough handling* of the child. Although even medical professionals could not always understand the implication of a nasogastric tube or ventilation. When her newborn baby was on ventilation, a mother was asked by a friend whether she could be breast fed. **"Are you on this planet?!"** Was the unvoiced reply!!



Interspersed in tonight's discussion were fragments of conversations parents had with others following the child's death. Being prepared and rehearsing a response can be helpful. Of course some comments as we were to hear, *come so out of this world* that they can never be anticipated! They will just hurt.

Here is a selection of some remarks:

"I know how you feel, my dad died... f... off,

what do you mean, it's not relative, he had a good life, old age, you die when you're old, that's meant to happen, (it's) relative to what happens in your life".

"There are people worse off".

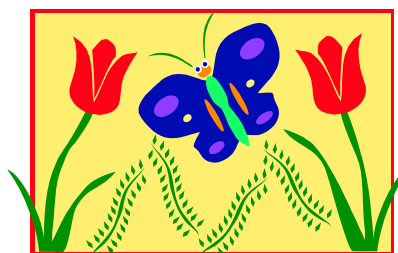
"God gives you what you can handle".

"How do you do what you do?"

"You're so strong".

We wondered whether such comments are meant somehow to be expressions of sympathy or encouragement. The feeling of the group was that it is insensitive and can make people very **"angry"**. There aren't choices and limits. Parents are dealing with what *life* has brought. As one father commented **"only people who know are people who have been through this"**. For example, it seems often parents who are not bereaved may be prone to complain about their children, such as being kept awake at night. **"Bring it on"** was one father's response. Sleep or rather sleeplessness is a subject that parents of children who have significant health conditions know a lot about. So too do parents who are grieving. Some parents shared their experience of *rest*. A few parents were sleeping only one hour a night. While others were sleeping in the afternoon, something they may never have done before. **"I have no energy, I know the lethargy"**.

Within the group as mentioned earlier there were parents who had been labeled *strong* by others. We thought about the *motivation* behind this. As one member of the group said **"they don't**



see me at home". Perhaps saying *you're strong* is a message or particular image to live up to. Could it be a warning not to show any distress? It's hard to know. The impression from the group is it's not the *whole story*.

Over the months since her daughter's death, for a mother in the group, there was an increasing sense of frustration and isolation. **"You all know what it is like sadly"** she remarked. Other people responded to comments about her grief other people say **"yep"**. It appears they really don't want to hear how it is now. **"I can't stop talking about my daughter, I don't think I ever will, she was here, it's good for us to talk"**.

The opinion she has is that she's had her *allotted* time of support. By now she should have *moved on*. Similar comments have been made in previous groups over many years. In thinking about the responses of other people towards bereaved parents, one couple spoke of how amongst their network, **"only one couple who won't talk... can't talk. ... They're not rude enough to shift the topic but they don't talk about her"**. Nor do they add to her parent's comments about her. It had reached the point where their family were considering perhaps they **"can't be friends... we've changed"**. A comment in response to this was **"a lot of things are clearer now... (I'm) not wasting energy"**

The group explored for a moment whether people were **"scared... they don't want to upset you"** Perhaps when they loved the child too they didn't want to open up, or touch their own pain.

There are all sorts of friends and their reactions can come as a *surprise*. One member of the group recounted what could only be described as one of the most *gob smacking* stories of insensitivity that has been told in the group (and over the years there have been some *show stoppers*). A friend could not understand how she (the mother of a little girl with a terminal condition) wanted to spend all her time with and energy on her daughter. While her daughter was alive, she resisted repeated attempts by the friend to become involved with her wedding arrangements and, to be a bridesmaid. Our *jaws dropped* with a mixture of disbelief, laughter and horror when the

friend at one point said to the mother **“she’s dead, what’s your excuse now?”** Understandably as other families have found, friendships may need to be reconsidered in the light of a child’s death. A father posed this salient question **“What does *she* contribute to your life?”**

On this night amongst the *chief offenders in the insensitivity-self focused- stakes* were mothers in law. **Please note** we know there are many many wonderful mothers-in laws *out there*. But there are others..... From the beginning they (the mothers –in law) argue about the diagnosis, treatment, and the choices parents made for their child. Some would have wanted funerals to be arranged around the dates they will be in the state (this was also a comment shared by the *bride* mentioned earlier!!) Others even on the day of their grandchild’s funeral were able to put their needs ahead of others and expected to be collected by the parents. *Mind you* from parents’ previous comments the child’s condition and dying had been viewed solely on how it impacted on her (the mother-in-laws) life. While others (grandmothers) never became involved or helped out during the child’s life. Some mothers-in- law couldn’t understand how the *first* Christmas’ might be painful and asked **“is there something wrong?”**



As we moved from people, to think more about places and experiences some parents said how they thought as they drove past the hospital **“there are people like us...you can’t help but think there are people sitting in Macca’s, looks like a nice family scene, but you don’t know what’s going on for them”**. Then again as one mother reflected **“others seem to have had it easy”** As one parent said **“I think there’s a whole other world, a sub culture that goes on”**.

In speaking about the hospital experience with their child, parents spoke about the impact of that time. Whether this time was measured in days or years, it touched parents in an indelible way. Visiting the hospital where her child had spent an all too brief lifetime was **“like going home”**. For bereaved parents who return to hospitals and revisit units, there was the recognition that parents currently with a child in the unit could be going **“through their own hell”**. Parents recounted

how healthcare staff of units were in a unique position in a family’s life. **“They knew her better than our family”**. We heard of the range of feelings held about returning to the Hospital unit where the child had been. It sounded like a feeling of perpetual connection, belonging and memory held within a knowledge that *life in the unit goes on*. Parents did not want *to get in the way* of other families currently in the unit. **“It’s their space now, when we were here it was our private space, we owned it”**.

Towards the end of the group thoughts returned to the time of a child’s death. These may be times that cannot be spoken of with other people. However, parents often want to revisit these memories. One father responded to a mother’s reflections about her child’s dying and death and the coldness and rigidity of her body by gently saying **“it’s really sad, it’s distressing to see them that way”**. Other parents in the group knew this coldness, a coldness never felt before. A sensation which signaled that all life had gone from the body. Within the group several parents had known the last moment of their child’s life. One mother had said she **“would do anything to go through that day again”** Her daughter’s last breath was almost imperceptible. It was “peaceful”. Those who needed to be with her were with her. While for others their child’s dying was experienced as a time when the child was in painful distress, leaving parents with traumatic images. As these extraordinary times were recalled, a parent explained she had been asked questions by her daughter about whether she would die. It was an awesome question which the mother answered carefully and honestly. Her daughter did not need to ask again it seemed. A parent never expects to have to answer such questions. These experiences mark parents forever.

Throughout the evening as parents spoke about their children, *some of what is most missed about them* was mentioned. This list which really is limitless included

“I miss her, I miss her voice”.

“His look”.

“I miss the night time cuddles”.

“ Setting the table for her...I still do it”

“I miss my time as a family, the three of us”,

During the evening parents showed precious scrapbooks of their child. Creating a scrapbook was described by one mother as **“part of my grieving”**. While one mother **I couldn't do it fast enough”,** another was finding it was taking time. She had to come to a pause and for the moment could not continue the *work*. We saw also beautiful books made by early intervention groups, pictures of children at crèche, photos of happy family groups. We glimpsed colour and contrast. We met a small toy dog who had accompanied a child and were introduced to a special rose. We smiled at photos of children smiling, pulling faces, playing, painting and being cheeky. We were introduced to children with their pets, with friends, with family. We met children who are loved in life and in death.

While the discussion drew to a close, these words from earlier in the evening echoed into the night: **“She brought us so much love, joy and happiness even if you knew, you'd do it again. If someone said to you there is a one in four chance of being hit by a bus, would you just stay in your room, you can't be... scared of everything, that's not living”**.

Before moving to supper we read the final part of the meditation by Carol Staudacher (1994).

My love is hard to bear during this time of mourning, but I know that my ability to love with such intensity is a precious gift that all do not share. I will be thankful for that gift and will remind myself that it is my direct connection to all the most worthwhile aspects of my life.

***Advanced Notice –
Annual Memorial Service***

The year the Annual Memorial Service for hospital patients who have died will be held on Sunday the 21st of August. Entitled **‘Finding a New Rhythm’**. This service will bring together families and members of the hospital community to honour and celebrate the children who have died.

Times for the afternoon:

1:30pm to 2.15pm to arrange photographs and mementos.

2:30pm to 3:30pm Memorial Service.

3:30pm – 4:30pm – Afternoon Tea

An invitation will be in the mail shortly.

Sibling group—an afternoon for brothers and sisters

The annual Brothers and Sisters afternoon will be held on Friday the 12th of August. This special afternoon provides an opportunity for children, who have had a brother or a sister die, to meet one another and share their story and memories. Invitations will be sent shortly—but please make a note in your diary to join with the Hospital community on these meaningful occasions.

Dear Parents,

Once again thank-you to those who responded to my request for suggestions on a name for a private space for bereaved parents in the hospital. We have received much information and valuable ideas from the three focus groups and you email feedback.

Twelve parents, one grandmother and a friend attended the focus groups. Their experiences varied greatly. Some parents had time to plan for the events leading up to and during their child's death whilst others experienced the sudden death of their child and in some cases were coming to the hospital for the first time when their child died. One mother was in the very early phase of her grief as her child had only died months before whilst another mother was coming back to the hospital 12 years after the death of her child. Many parents said the involvement in the focus group was to help future parents who have to experience the death of their child. Some described it also as a way of honouring and caring for their own child who has died. The different experiences of each parent and grandparent provided a wealth of information and ideas.

The participants were given the guiding statement, of what are the design principles that should be considered in the redevelopment of a room for bereavement at the RCH. In answering this question the participants drew on their own experiences and provided valuable information on the design of such a room as well as staff training and service provision. All the insights and ideas will be used if not for the design of the room then for the development of the guidelines for care when a child dies, staff training and resource development. We are looking forward to gaining further understanding of these issues over the year.

Below is a summary of the suggestions for the bereavement room followed by a summary of the insights relating to service provision and training. Please feel free to contact me if you have other suggestions.

Design principles for a bereavement room at RCH.

The room needs to be dedicated to bereavement care rather than a multipurpose room. Families should not feel that staff have had to move out of a room they use. Neither the staff nor the families should feel intimidated.

The room needs to be easily accessible to the mortuary without being close. It should be away from busy areas of the hospital such as emergency and have a sense of privacy without being isolated and out of the way. Staff should be available to manage the space without intruding on the families privacy. A telephone should be available to contact staff as they are needed. A screen or partition in the doorway could allow additional time for people to prepare themselves before they are seen by those entering the room. The room needs to be secure. No-one should enter without permission. The room should also offer easy access to the chapel and outdoors.

The room should be large enough to accommodate big families without being so large you feel lost; a space to embrace. It should have a separate space for staff to talk with families. Two spaces would offer some family members the opportunity to have private time with the child whilst other can be in a quiet space nearby. The room should include or have access to:

- toilets and bathing facilities
- comfortable chairs to nurse your child and for breastfeeding
- a bed or settee to lie down with your child
- a phone and phone book for contacting family and friends
- resource information
- entertainment for siblings such as books, videos and pencils
- facilities for recording events such as digital camera, plaster moulds, and memory albums
- a CD player and choice of CDs
- refreshments including tea and coffee making facilities
- a private courtyard

There should be a sense of tranquility and security in the room. It needs to be a safe and comfortable space, where I would want to leave my child. Running water or the sound of running water could help give a peaceful ambience.

The room should be simple and uncluttered. It could be decorated with a theme. One suggestion is using the imagery in *The Next Place* book. There needs to be natural light and ventilation. The space at Very Special Kids is a good example for design principles.

Lastly, the name of the room is important. It should not be called a viewing room or visitation room. Some suggestions for a name are the harmony room, the lavender room (decorated to suit the name), resting place and the sanctuary.

Ideas for improving care of families when their child dies.

Some of the insights that came from the participants experiences and ideas are listed below:

Care of the child who is near to death should involve minimal interruptions, prompt and adequate pain relief and no restraints on numbers or timing of visitors. Staff need to introduce themselves and be clear what they are there for. Staff have a role in managing or assisting families to manage visitors. Staff should offer to contact family members and should ensure that families have food available. Staff should provide information to parents about:

- what to expect
- palliative care options and services
- choices they have in the way they spend time with their child
- funeral directors that are good with children
- support services

The information needs to be provided simply and clearly and should include a checking back to see what parents have understood. Staff should actively refer families to support services not leave it up to them. Staff need to be aware of their importance to some families (when left the hospital, we lost our family but also allow the family their privacy, staff kept coming in to say good-bye). Staff should ensure families are provided with the option to take their child clothing with them, no matter how bloody, ripped or torn garments may be. Staff should support families in leaving the hospital and ensure they have a safe way to get home.

Parents should always be allowed to be with their child no matter what is going on. Parents should be offered some choice in the staff that are allocated to them. Families should be able to stay with their child for as long as they want to and not feel rushed. Parents should be able to go with their child to the mortuary if they want to. Parents sometimes want to come back to the ward and spend time with the staff that cared of their child.

Once again thank you to all who have offered their experiences and insights. I will keep you informed of the plans for the bereavement room and other ways we are making use of your valuable ideas.

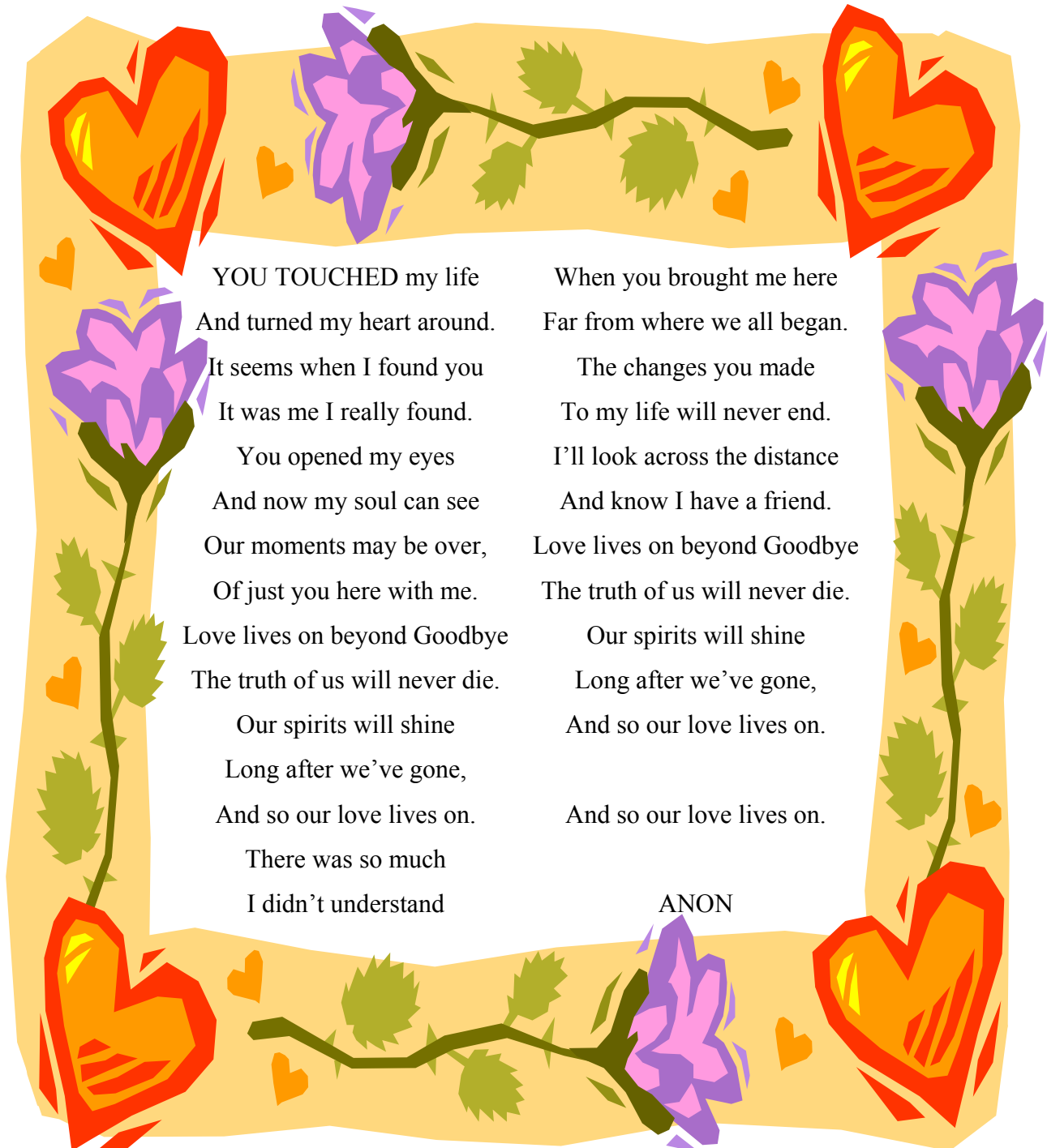
With best wishes



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Straight from the Heart

This month we are without a piece written by a bereaved parent or other family member so we have included these words from Emily Dickinson and an anonymous author.



YOU TOUCHED my life
And turned my heart around.
It seems when I found you
It was me I really found.
You opened my eyes
And now my soul can see
Our moments may be over,
Of just you here with me.
Love lives on beyond Goodbye
The truth of us will never die.
Our spirits will shine
Long after we've gone,
And so our love lives on.
There was so much
I didn't understand

When you brought me here
Far from where we all began.
The changes you made
To my life will never end.
I'll look across the distance
And know I have a friend.
Love lives on beyond Goodbye
The truth of us will never die.
Our spirits will shine
Long after we've gone,
And so our love lives on.
And so our love lives on.

ANON

Unable are the Loved to die
For love is immortality

EMILY DICKINSON

Contributions such as poems, letters, songs, orders of service quotations from parents, grandparents and friends are most welcome in the Newsletters. Share your thoughts, experiences and questions with others who are bereaved.

Please forward them to:

The Editor
Parents' Bereavement Support Group
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PARKVILLE VIC 3052



Our letterbox is empty!

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

Thursday 21st July
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 Heather McLaren**, Consultant and Bereavement – Manager Support Services John Allison Monkhouse Funeral Services. Heather, who is a grief counsellor and educator will lead an exploration of the theme **'My Grief – Our Way: The Influence of Family, Community and Culture on How Parents Grieve'**.

Please join us for this important discussion.

The newsletter is a team effort. Thank you to the parents of the Parents' Bereavement Support Group, Carol, Jane Miller (Chief Social Worker), Jodi, Rebecca and Aleisha for their enormous assistance with the creation of the newsletters and to the Social Work Department for its ongoing support.



Jane Sullivan
Author & Editor