



FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department
Royal Children's Hospital

NEWSLETTER JULY 2009

Welcome to the Royal Children's Hospital's Family Bereavement Support Programme's Newsletter. This Newsletter is unique because it focuses on what is said during a particular monthly Bereavement Support Group, and because it contains the words spoken by people who attend the Group. We hope that as you read the reflections of the parents who attended the Parents' Bereavement Support Group in July 2009, you will share a connection with their thoughts, feelings and behaviour, gain an increased understanding of what you are experiencing, and find hope for the future.

'Trauma and Grief: a journey without maps'

Thirteen bereaved parents, including five fathers, attended the Parents Bereavement Support Group in July. The children who had died were aged between a few months and fifteen years of age. Of the seven much-loved children who were represented within the Group, some had died suddenly, others had died after long illnesses, and the time which had elapsed since the children had died varied between a few weeks and two years.

The Group was co-facilitated by Carol Quayle and Vivienne Bateman. John Downes, Social Worker / Manager, Road Trauma Support Service, led the discussion, which was, in part, focused upon trauma reactions.

Trauma and grief

Grief following the death of a much-loved baby, young child or adolescent has, almost always, an element of trauma attached to it. In some cases, this is because of the suddenness and unexpectedness of the tragedy, such as following a road accident. In other instances, the time of diagnosis is known to be a traumatic experience. And, as John Downes noted: "During a prolonged illness, 'places' along the way, interaction with medical



staff and other events, have the potential for intense distress. And, in other cases, the decision to turn off life support is a traumatic event in itself." Significant psychological trauma has been likened to a 'psychic wound'. As if to emphasise this point, one parent said that her "**heart had been blown wide open**" when her beloved child died.

While trauma and reactions to trauma are now receiving quite a lot of attention in the media, and are being responded to by health professionals and others, the journey following a traumatic event such as the death of a child is, as John Downes stated: "a Journey without Maps", resulting in "bereaved parents finding themselves walking in unknown territory". Becoming informed about normal reactions following trauma is known to be helpful for bereaved parents and others who have had a similar experience. A list of contact details for organizations which provide information about trauma and grief, and ongoing support for bereaved parents and children can be found near the end of this Newsletter.

The 'journey' through a child's illness

Parents whose child had endured a long illness explained the "**peaks and troughs**" as they "**navigated the storms of the illness**". One parent spoke about "**running out of steam**" at times during her daughter's "**battle to stay alive**", and

how hard it was for her when her daughter asked: "**Mum, what have I done wrong?**" The emotional roller coaster, exhaustion and sense of helplessness felt prior to and following a child's death is well-known to parents and other family members who attend this Group and other bereavement support groups.

Turning off life support

One mother said: "**Making the decision to turn off life support was the hardest decision we have ever had to make.**" She added: "**We left the Hospital wondering if we had made the right decision ... that's a terrible question to be left with.**" For this mother, speaking with her child's doctor a few weeks later, helped to allay some of the doubts, concerns and fears she had.

The unfairness of a child's death and the associated pain

A mother whose six year old son had died in a tragic road accident said: "**You never think one of your children will die ... you never think it will happen to you.**" Another parent explained how "**(her) heart peeled open**" when her daughter died. She was left feeling "**open, exposed, distraught and vulnerable**".

Dealing with anger

Other parents expressed the overwhelming anger they felt about their children dying. One parent said: "**My anger is massive! It's hardened me up.**"

I find it hard to sympathise with silly things ... little things that upset other people ... they don't matter ... I don't waste time on them now ... Another added: ***"At times I am scared by my own anger ... I'm scared I'll dump it in the wrong place ... my grief and anger don't seem to have a boundary."***

While expressing anger may help to make you feel a little better for a short period of time, if it seems to be out of control and goes on for an extended period of time, or is affecting your relationships, it might be helpful to talk to someone you trust. This may be your GP, a counsellor or a trusted family member or friend.

Lessening feelings of isolation

Parents spoke about how, since their child's death, they had experienced a sense of being isolated from others. ***"The level of grief I feel has made me feel as though I am cut off from other people ... I feel like I am an alien in our own world."*** While this is a common response following the death of a child, it is important to try to keep in contact with supportive family and friends, particularly those who knew and loved your child. You may need those people to be around you in times to come, and hopefully they can share precious memories of your child with you in the future.

Do men and women grieve differently?

It is acknowledged that ***"different people have different styles of grieving."*** This can mean that ***"it can be tricky for some couples."*** Sometimes, the way some couples

interact can lead to some partners ***"doubting themselves when an island develops in the relationship."***

When partners grieve differently it is important to understand and accept this. Because both parents may be feeling overwhelmed with grief, the sharing of feelings can be difficult, and at these times it can be helpful to speak with an understanding friend, relative or other support person.

Further, as John Downes explained: ***"Women are known to be good at expressing emotions, talking face-to-face and so on. But***

if we take the time to sit with men, they too can express their emotions. Men can be very understanding and compassionate. We just need to give permission to men in a 'manly way'. Women sit and talk, men stand and talk. Some men are more articulate than others. Some men would rather do things or build things in preference to talking about things. But they are still grieving even though they may not be telling the story".

What about the other kids?

Brothers and sisters of the child who has died can sometimes be overlooked, but they grieve too – sometimes silently and when they are on their own. Because they don't want to see their parents suffer, many children and adolescents worry about their parents and other grieving family members. One mother spoke about how she senses that her surviving children ***"suffer jealousy because of my feelings for (my daughter who died). I don't want them to feel that way and I want to have more time and energy to give to them."***

Passage of time

Choking back tears, one mother said ***"tomorrow my daughter will have been dead for as long as she was alive. I have now lived without her for as long as I lived with her"***. This, like other milestones, can be a significant point in the grief 'journey'. She continued: ***"At the moment it's hard to remember the happy memories ... but she really was a happy and cheerful little girl, even though she was so sick."***

Resilience, growth and the ongoing journey

Parents spoke about how their children had been ***"a Gift"*** in their lives and that the whole experience of sharing their lives and the times since they had died had ***"made (me) a better person. It's made me more 'human'."***

One mother, whose daughter had died over two years ago, explained that she had embarked on ***"an unending journey"*** and that it has ***"been an intense emotional journey"***. She continued: ***"While there are still bad days (I) am enjoying life again. I poured myself into my work; it helped me to keep busy."*** Another parent said that she had ***"grown around the pain and (has) found joy again"***. She added: ***"Everything changes over time. I've found that I have had to 'unpack' my life. Some things that were important before are no longer. I've had to***

simplify my life."

Being with and supporting other bereaved people

One parent said: ***"I need to be with other parents who understand."*** Another added that since her daughter died she has developed ***"a unique understanding of grief"***, and is finding herself ***"in the position of supporting other bereaved people. I am able to sit with them and I can explain to them what I have experienced, and how I have coped with the various aspects of grief. This seems to help them."***

The telling and retelling of the story

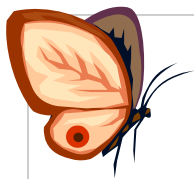
While acknowledging that some people, particularly men, may prefer not to do so, it is known that telling the story of what happened can be an important aspect of adaption to / accommodation of traumatic experiences (Neimeyer, 2004; Gordon, 2004). As John Downes said: ***"It can be helpful to revisit the memory, and while this can be distressing, if done with a competent professional, this process can be very beneficial following trauma."*** As one parent explained: ***"I have to let some of what I'm feeling out ... I also have to let the grief out ... Sometimes I give myself the freedom to be sad if I want to be"***. It is important to tell the story of what happened to someone who understands and ensures you are "kept safe" during and after the retelling.

In addition, speaking about your child's life and all that it entailed is known to be part of the ***"healing process"***. This can be particularly so if you are able to speak with people who also knew and loved your child. Further, retelling your experience within an environment where others have shared a similar experience (eg at the Road Trauma Support Service, SIDS and Kids, The Compassionate Friends), has also been found to be supportive. (See contact details of these and other relevant organizations below).

Our child's special, endearing qualities

It is very evident that bereaved parents maintain a 'continuing bond' (Klass, Silverman and Nickman, 1996) with their child. This bond is frequently expressed when parents speak with pride about their children's special and endearing qualities. It is also acknowledged that as parents, we have ***"a sense of how wonderful our children are"***, and that ***"the love and affection we have for our children is probably the most meaningful love any of***





us experience". When asked about special or endearing qualities their children had, parents responded in the following ways:

"He had this huge smile. He had all his teeth by the time he was eleven months old, and they just shone through when he smiled"

"He was full of character; very generous (he would give all his toys away); he was expressive, open and full of energy."

"She called me 'Mumsy'"

"She had pink hair ... it was her way of coping with the fact that it would ultimately all fall out".

"She had big, bright, eyes. She smiled through it all. She was 'a wise soul', even though she was only five months old."

"She had very beautiful eyes ... you would just drown in them."

"Because he couldn't speak, he talked with his hands ... He would get all excited and use his hands to say 'Ooooooh. Thomas the Tank Engine!"

"We called him Bodey ... he was such a cheeky little monkey"

"Our children were happy"

This theme was continued as a number of the parents within the group spoke about how happy their children had been, and how, as parents, they had devoted themselves to giving their children as **"good a life as possible"**. One parent added: **"It might sound like a strange thing to say, but he'd want me to enjoy myself and to make the best of things."** And another, **"He was happy with life ... that is the gift he gave us."**

Self care

As John noted, the need to look after ourselves **"during the long journey of bereavement cannot be overemphasized"**. Reading, writing, listening to music, talking, attending support groups, going on fishing trips and golf days for bereaved fathers, as well as attending memorial services are some of the ways known to provide solace, understanding and comfort along "the journey".

Summing up:

A peaceful and almost sacred space was created during this Meeting. Perhaps this was a result of the calm demeanour of John Downes (the guest co-facilitator), or perhaps it was simply a reflection of the love for the children which is always fully displayed within the Group. While the sadness in the room was, at times, palpable, a gentle warmth was also evident as the parents who were present, listened carefully and intently, and shared their depth of feelings, some humour and their learned wisdom with each other.

Vivienne Bateman
(BSW, MAASW, MH Accred.)
c/o Social Work Department
Royal Children's Hospital

References

Gordon, R (2007) Thirty Years of Trauma Work: Clarifying and Broadening the Consequences of Trauma, in Physiotherapy in Australia, Vol 13 No 3 May 2007

Neimeyer, RA & Currier, JM (2008) Bereavement Interventions: Present Status and Future Horizons, in Grief Matters Vol II No 1 Autumn 2008

Klass, D, Silverman PR & Nickman, SL (1996) Continuing Bonds, New Understandings of Grief, Taylor & Francis, PA

Bereavement Support Organisations

SIDS and Kids Victoria
Ph. 9822 9611 / 1800 240 400

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

SANDS (Stillbirth and Neonatal Death Support)
Ph. 9899 0218
www.sands.org.au

Provides parent support groups, one-to-one parent support, publications for parents and health professionals

Road Trauma Support Service
Ph. 9877 7922 / 1300 367 797

www.rtstv.org.au
A statewide counselling, education and support service for people who have been affected by road trauma. Services are provided to bereaved family members, drivers, passengers, witnesses and their family and friends.

Compassionate Friends
Ph. 9888 4944 / 1800 641 091
www.compassionatefriendsvictoria.org.au

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

Mercy Western Grief Services
Ph. 9364 9839

A bereavement counselling and support service for people living in the western suburbs of Melbourne.

Very Special Kids
Ph. 9804 6222

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

Bereavement Counselling Service
Australian Centre for Grief and Bereavement
Ph 9265 2111
www.grief.org.au

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



Straight from the Heart

The following poem was written by his mother Rebekkah, after Sean Taffee died tragically. Thank you Rebekkah for sharing it with us.

Sean Patrick Taffee

22/01/04 - 11/03/07

Your smile and your cheeky laughter,
The way you would sing
Your own special dance,
That you would so often do
Your frog imitation,
All parts of you
The small little things
Are what I long for you to do
Wrap your arms around my neck
And whisper "Mum I love you"
Over the years,
Watching you grow
With your love,
I've learned how to show
All the goodness,
I learned to hide
For reasons so old and tired
You made my life have meaning and purpose
Enabled me to find my true spirit
This is what you were sent here to do.



Our letter box is waiting!

Contributions such as responses and reflections on the groups' themes, poems, letters, songs, quotations from parents, grandparents, brothers and sisters and friends are most welcome in the Newsletters. Share your thoughts, experiences and questions with others who are bereaved.

Please forward them to:

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Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Phone: 03 9345 6111
Or email: carly.blanche@rch.org.au

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

**Thursday 20th August
7:30 pm – 9:30 pm
Seminar Room 2, 4th Floor
Front Entry Building
Royal Children's Hospital**

In the August Group we will be joined by
Colin Charles, Social Worker with the
Bereavement Counselling Service, Australian
Centre for Grief and Bereavement. The
topic will be "Kids Grieve Too".

Please join us in August

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

*Vivienne Bateman
Editor*



The Royal Children's Hospital Annual Memorial Service

You are warmly invited to attend the Annual Royal Children's Hospital Memorial Service which will be held on:

**Sunday 30th August 2009
in the Ella Latham Theatre and Meeting Room, First Floor,
RCH Main Building, next to Café @ The Children's.
Doors open at 1.45pm. Service begins at 2.30pm.**

Afternoon tea will be served. If you would like to have your child's name read out during the Service please call the Social Work Department – 9345 6111
or email: memorial.service@rch.org.au
by Wednesday 19 August 2009