

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER NOVEMBER 2017



Welcome to the November newsletter of the Family Bereavement Support Programme. We hope that in reading the newsletters and being a part of the groups you will find connection with other parents, support and encouragement to help sustain you as you grieve for your child.

“The dilemma of investing in life while remembering and honoring your child”

This month's topic was “The dilemma of investing in life while remembering and honouring your child”. Stroebe and Shut (1999), writing about grief and bereavement, talked about the “dual process” of grieving as being alternately loss and restoration focused, whereby focusing on grieving for your child on the one hand, and focusing on coping with and being part of life, on the other, are not linear processes but a movement back and forth between the two.

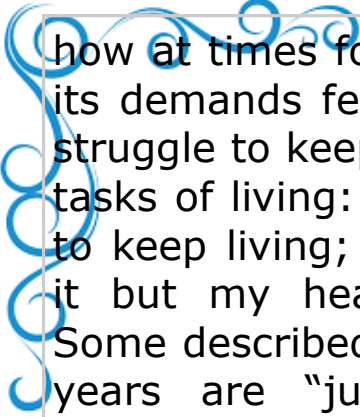
In this month's group parents shared some of the ways in which they

grieve and the ways that they manage to go on with life and living.

We began by hearing introductions from each participant, brief sharing about their child and their situation, and initial thoughts about the evening's topic. There were a mixture of group participants, many of whom have been recently bereaved, and others for whom it had been several years since their child died, who were able to reflect on how their grief and life focus had changed over the years.

Several group participants talked of





how at times focusing on life and its demands feels “forced” and a struggle to keep on with the daily tasks of living: “I know you have to keep living; I should be doing it but my heart is not there”. Some described how the first few years are “just surviving and getting through”. Parents spoke about moments where you “forget” that you had a child, and time goes on as if on “autopilot”; you are just “going through the motions, zombie-like”. “We are stuck in this life, with no choice but to keep going on”. One described that “others’ lives move on and people don’t ask about [our child] anymore”. This makes it particularly hard to be involved in daily life, when your own life and reality feels so at odds with other people’s. Several parents spoke of feeling totally changed in terms of who they are - a “different person” said one. “I will never be the same person”, another agreed.

Two parents spoke of the disconnect between the grieving self and the one that keeps on with life as being a person whose self is “split in two”. “There are two me’s - one who struggles day in, day out, torn up inside. Other me goes to work and holds it together”.

Group members spoke a lot

about work and how it functioned, or didn’t, for them. One mother talked about how she and her partner navigated the demands of daily life differently. She expressed that getting a job is not what makes her or drives her. For her, opting out of the usual things like work has been important, whilst her husband chooses to go to work: “He gives me the option to opt out”.

Other couples agreed that their respective ways of grieving and going about life were very different. One mother stated “Life is so different for the rest of my family (sisters and mother). I’m not really living life. Some people think getting a job will help, but I’m different”. In these ways for some group members work had not been helpful. However for others it is a way to be in life. One mother stated “I have to go to work. I can’t think about what I’m going to do in twelve months’ time. But I need work.” This group participant has gradually increased her hours which was possible with a supportive employer. “I couldn’t have stayed at home; I needed distraction. I cried to work and on the way home again. It gave me time in the day I could focus on other stuff - survival - otherwise I would not have got out of bed - I would’ve pretended the world didn’t exist”.

In this way work as a survival mechanism can coexist with the distress and grief.

One mother spoke about her need for retreat and the fact that others “don’t understand complete retreat. It’s still really raw one year on.” She writes a blog and does not find it painful, but sees it as expressing the reality for her, her partner and child. “It’s the truth. When we walk away from his monument at night I say goodnight, it’s not fair or normal that he is there. I started the blog on his first birthday. I still write, I feel like I’m in a time warp. Two years ago life was ok”.

Other group participants spoke about the movement back and forth between working and grieving. One mother pointed out that it is important to have both work and a space to retreat to. She spoke about the importance of being able to retreat to grieve and then “step outside” it. Going to work for her gives a purpose. “It’s nice to connect to others and also to retreat. If I didn’t have both I would have lost it”.

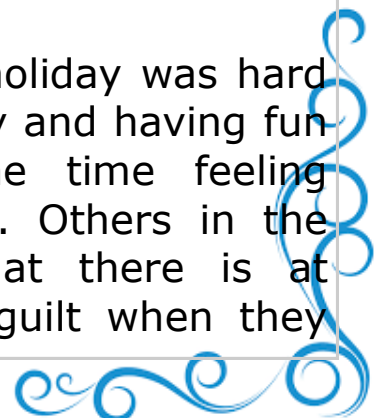
One father attending the group felt that work was important for focus: “I want focus. It’s nice to see colleagues”. Another did not find his employer supportive after the loss of his child. Having had a car accident in the past, he com-

mented that he got more support after this than after the death of his child. In this way whether work is helpful or not sometimes depends on the level of support the workplace provides. He commented that what is important is to “find something that is worthwhile – it does not have to be work”.

Another parent spoke about how your sense of priorities changes after the death of a child. “Your focus on life changes. You build a house, but you want your child. You wonder why you bothered going to work, you ask why didn’t I stay at home with him? And why do I bother now as my employer is not supportive?”

Many parents in the group spoke about finding things to do which both honoured their child but also helped them be part of life. One mother shared that she and her husband recently went to Disneyland because it was somewhere that they had always wanted to take their child – thus continuing active life but in a way that honoured the memory of their child.

Despite this the holiday was hard as they were busy and having fun yet at the same time feeling guilty about that. Others in the group agreed that there is at times a kind of guilt when they



catch themselves enjoying things. "It's a conflict"; one stated, "it's hard. I catch myself enjoying myself (and feel guilty). But I wonder what he (their child) would want. He doesn't want me to be in a puddle of tears".

Several parents spoke about this sense of living life the way their child would have wanted to. One mother spoke about the promises she and her partner had made to their child who died about the way they would live in the future – leading more active and healthy lifestyles and not taking life for granted. At times they realise they are not fulfilling these promises – but what they have more successfully been able to do is to focus on the promise to "laugh and live and love". In this way paying tribute to your child also can give you a way to approach your life without them.

Speaking about stories and memories, writing about your child or writing your child a letter, scrapbooking, placing objects like windmills in their memory, or



growing a garden for them, were some of the other ways group participants spoke about honouring their child

in their life now.

Whilst all agreed that it was entirely insensitive and unhelpful when people assume that having another child could replace the one who died, several group members spoke about the role siblings have played for them in anchoring them in life again.

One mother whose child died some years ago said that in having a second child "hope came back and there was a purpose again". She described how it does get easier and how writing a journal had been helpful. Originally the journal was started for her first child but following his death this turned into something that his siblings can connect with.

Another mother talked about how having to feed and look after the siblings meant she had to invest in daily life. However she described that it took quite a while for her to find happiness through her other children. One couple talked about how they "pour the love (for their child who has died) into the siblings, make promises to give them a great life that he would have had".

Another mother, whose child died ten years ago described that it is still hard and that she had "no purpose" in life until a sibling came along. However she also

acknowledged "That's a lot of pressure for one boy". She also described that the enjoyment of seeing this sibling riding his bike is still saddened by the knowledge of simultaneously knowing that her other child will never do that.

Parents spoke about how doing things with the siblings which honour and remember the child who died can help create connection between the departed child and the family members left behind. One mother shared that she had taken the siblings to the helipad to play as it was the only physical space from the old hospital where her son had been. In this way it was a shared place for all the children to be in the same space at the same time (which they otherwise will never have the chance to do).

Traumatic memories can also make engaging with daily life a lot harder. A number of participants spoke about still clearly remembering the events leading up to their child's death, some group members identifying their reactions as symptomatic of post-traumatic stress. "People forget about all the stuff in-between", said one mother. "Everything happened in hospital. I remember every day

when he was unwell." Many found that these traumatic memories were particularly re-



nited at anniversary times such as the month of their child's death. One stated at this time "I relive every day from the beginning until the day of death."

Another mother who had lost her baby, felt triggered by returning to the hospital. "I feel like I'm sinking when I come back. Each day you would get bad news. I get a knotted stomach". Even the familiar smells could set off a traumatic response.

However, others in the group found it sustaining to come back to the hospital, smelling the lift and even the hand sanitiser, as for them it brings a sense of connection with their child. Many still feel a connection with nursing staff and wonder if those who cared for their child will still remember them, acknowledging that "nothing stays the same" even though a bereaved parent can feel like for them "everything stops in time" when their child dies.

The process of grieving and the process of investing in life can

often feel mutually exclusive and indeed, as described above, many bereaved parents feel like they swing between these two states, often struggling to reinvest in a life and a world which continues to move on and often does not recognise grief and the needs of griever. Also, parents describe the need to hold on to grief to hold on to the connection with their child.

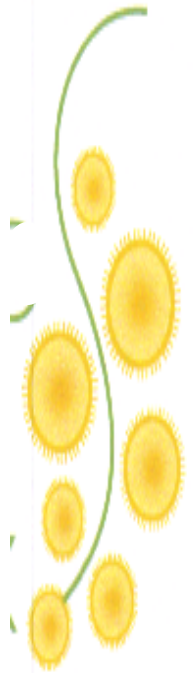
Nevertheless, the grief does change over time as does one's ability to engage with life again. One parent commented that "One day I realised I hadn't cried in months and I realised it's ok. But it took time. Another parent concurred: "The grief now is different to when we lost him. Everything changed".

Group members were able to share their own particular manner of continuing to find ways to be part of life whilst still carrying their grief and their memories with them in that life. As one mother stated of her child: "He is there in everything we do. His siblings draw him with wings saying that he is a part of my family". She described a shift in focus over the years of living with grief: "Rather than remembering, he is with us living life".

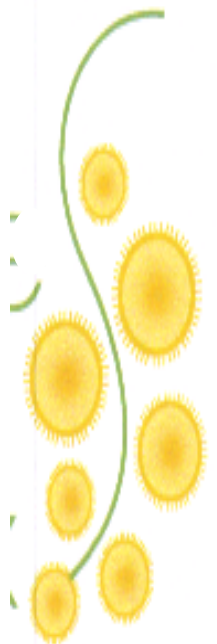


Thankyou to the parents who generously shared their thoughts, memories and feelings with each other in this months group.

Straight from the Heart



These lovely photographs have been taken by one of our parents Mary Lin, with thanks



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, feedback about this newsletter are most welcome. Share your thoughts, experiences, questions with others who are bereaved. Please forward them to:

Family Bereavement Support Programme
Social Work Department
Royal Children's Hospital
50 Flemington Road
PARKVILLE VIC 3052
Phone: 03 9345 6111
Or email:
bereavement.services@rch.org.au

****If you would like to receive
the newsletter by email
please send us your email
details to the provided
address.****

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

**Thursday 14th December
7:30 pm – 9:00 pm
The RCH Foundation Board Room
Level 2, 48 Flemington Road
Parkville, VIC 3052**

Please join us to discuss the topic:

“Tis the season to be.....? Grief in the season of celebration”

Please join us in December.

*The newsletter is always a team effort.
Thank you to Robyn Clark for facilitating, guiding the group discussion and writing the newsletter
and to Jasmyne Mack for scribing parents' statements.
Also to the RCH Volunteers for mailing assistance & to Jenny Jelic for ensuring
the newsletter is typed, formatted, collated and distributed to interested people.*

Social Work Department, RCH

