

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER JUNE 2018



Welcome to the June 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.

*“Where did the old me go, who am I now
and how do I let people know?”*

The group began with introductions from the thirteen group participants, some of whose children had died many years ago and some whose loss was more recent. These included two mothers bereaved ten years ago and another who is looking after the still hospitalised sibling of her child who died, dealing with both the acute grief for the one child who died and the rawness of being in the hospital every day remembering this and worrying for the other child. The differences in time of bereavement and specific circumstances of each parent's loss do not detract from group interactions but rather enrich them, as differences as well as similarities are shared.



Those whose loss is painfully new can share their raw grief and be around others who understand it, whilst those who have been carrying their grief for a longer time are able to give some sense of how they manage to do this further down the track.

Many still recall traumatic memories from the time around their child's death (for some the huge shock at a sudden unexpected death, for others the experience of hospital, genetic investigations, the waiting, self-blaming thoughts afterwards and questions of whether anything else could have been done). One mother bereaved ten years ago returned this night after not attending the group for many years, as the topic

had been perplexing and engaging for her, wondering about how she has changed or what has changed over those years. She read us an evocative poem she had written pondering this, which led us in to the topic of the evening.

Parents spoke about the sudden dramatic change in their lives when their child died, and how important self-care is in the face of this. One couple in the group had recently taken a holiday for self-care despite how hard this was to do without their child. Another parent agreed saying her child's death totally changed her life but stated you do find ways of carrying on with your life. It necessitates "**a new existence**" which she has learnt to live with, even though the death of her son at times "**feels like yesterday**".

One mother whose second child was born shortly after her first died, spoke of the timing and the sense of both blessing and curse, and how she still grieves every day, but "**it just evolves**". Another couple spoke of feeling like they were in a "**cycle continuing to go around**", with fluctuating focus on grief and then on the life of their child.

Several in the group spoke of the sense of being a different person since their child's death. One mother spoke about how she used to be an extremely positive person but came "**unstuck**" after her daughter's death, experiencing herself as a changed person with a

different identity. A mother whose son died 8 ½ years ago, also stated she is not the same person she was before. She has since had another child and wonders what kind of parent she would be if her first child's death had not happened. "**If I'm so changed, how would they have changed? The grief is there after all this time but different**".

One father talked about how his child's death had changed him, comparing himself now to an older person who has little tolerance for others' foibles or insensitivity. Other parents agreed they had little patience for "**bullshit**". This father stated that his friendship group had surprised him, with many turning his grief into "**their own thing**". This father states he has shed those friends, and feels this was necessary and normal in the circumstances. However he doesn't want to be bitter forever, the one without joy, doesn't want to be the "**downer**" forever. He came to the group to see what other parents have experienced, and find out whether it gets better. Another father responded to this, sharing his own experience as a previously "**fun loving**" person before his child's death and need to rebuild himself afterwards. He and his family lost what he saw, looking back, as an essentially perfect life, and he reports it has taken him four years to slowly "**build a new version**" of himself, carrying the scar with him as "**emotional baggage**". Early on he didn't think life was worth it, and understands

that perspective. However he can now see that his journey didn't end when his son died. He described that he and his partner got up **"a day at a time. It was just survival at the beginning..."** but he is now able to be excited about life and experience joy. **"We let some sun in, we're excited about the future... we don't ever forget though"**. Other parents expressed that this was helpful to hear.

Some parents spoke of how hard they have been on themselves since their child's death. One mother whose son died some time ago, discussed her difficult self-blaming thoughts, feeling that she didn't fight hard enough for him and should have done other things and sought other treatments. Though she remembers feeling very raw, she acknowledges this has passed though angry feelings can still persist and these are worked through over time. Another mother related to this, reflecting that she is **"in a stage of anger that people just don't understand"**. She voiced the frustration that the old life is gone, **"it will never be the same, it's just different"**. She talked about how people assume in what they say or ask, that **"the old you will come back"** whilst she feels **"no it won't"**. Some parents



would prefer others to just say nothing rather than comments which seem totally insensitive.

This topic of people not understanding is one that commonly arises in the group. The mother whose child is still in hospital after the death of her sibling, expressed her distress that family members have not been offering the support or contact that she needs. Other group members wondered if family members may be struggling to know how to be supportive in a situation that may feel confronting or discomfiting to them. There was some discussion between group members about the fact that unfortunately family do withdraw at times, often

worrying about **"doing the right thing"**, however there was general agreement that there is no **"right thing to do"**. One father confided that his dad hasn't been in contact since his son's funeral, and reflected that this was because he is not emotionally able to support him at this time. Because of this, he acknowledges that he cannot **"prop his dad up right now"** – this realisation helps him get through the **"disconnect"**.

One mother reflected that her mother in law relationship had been very difficult to navigate or receive

any support from. She stated she had to lower her own expectations of what she wanted from her mother in law and other people in her life as her expectations have the ability to **"wind her up into a knot inside"**. She explicitly told her mother in law in an email what she needs in relation to acknowledgement of her son who died, and says that since this her mother in law has in some ways been able to **"come through"**, underlining the importance of telling people directly what you need. She also acknowledged that other parents who have lost children have been a major support and able to provide what she needs, and this was echoed by others in the group.

Others felt lucky that they had good support from family and friends, but still struggled e.g. when key dates are acknowledged **"only on Facebook"** and not in person. One couple asked others whether they should **"shed"** friends who seem unable to understand or have the capacity to empathise with them right now. Some wondered whether people's incapacity to empathise was to do with their age or lack of experience. One father commented that these difficulties are not necessarily about age or experience but rather **"an emotional maturation thing"**.

One mother reported that she has not gone back to her normal routines, and has a friend who is confronting her about this, using language which feels very

uncomfortable to her. She feels they are not **"backing off"** and not recognising the change that has occurred for her. This frustration also feels more stressful as life has now brought other stressors since her child's death with her own mother now being seriously ill. This mother also raised the fear that if you look like you're laughing and getting on with life people will think you are **"over"** it. Another mother related to this, feeling she made a mistake going back to work and putting on her professional face, people think she's okay and coping so she is now unsure of how to get support, let them know that she isn't doing okay and she's not the same person. As many bereaved parents often acknowledge, the death of your child isn't something you **"get over"**. In fact, holding on to memories of your child, and to your grief at their loss, can be a very important part of how you continue to live life.

Some group participants expressed that they would like others to understand for a couple of hours what they experience. **"It's the club you never want to be in. The greatest fear we have is that something happens to our child"**. However some parents also acknowledged that it is way too difficult for someone to understand who hasn't been through it, and they wouldn't wish that understanding on others. One parent stated **"I'm happy none of our friends understand, but it**

makes us very lonely". Others reflected on having to deal with their new sense of the future as **"the long future ahead without your child"**. A few parents pointed out that perhaps at times their expectations of other friends and family to know what they need, might be too high, as often it is even hard to work out themselves what they need, let alone tell others.

Some parents spoke about how they now live to give to their other children. One father stated that he and his partner **"now live to give our other son happiness in his life"**. He reflected that he

tries to have compassion within his grief, and is a very spiritual (though non-religious) person, feeling he has an obligation to their son to be **"his beacon to surround him with compassion, and smile and laugh and move away from losing light"**. Having another child was also seen as a blessing in bringing a responsibility to guide him. He stated he tries not to hate the world, envy other people, or wish it to be different. He acknowledged that though this attitude is not right for everyone, it works for him and his partner.



Another father spoke of the double edged sword of celebrating but also being in pain at the arrival of a new child. Yet another parent stated that when her second son was born he brought her purpose, **"it was a conscious choice to see the light. This has been less of a conscious choice over the past 3 - 4 years, I don't have to think of doing I now, it naturally happens"**.

Some parents spoke about being able to reinvest in life by living in homage to their child:

"We promised (our child who died) we would live and laugh again". Several identified in their changed sense of self a new realisation of

love, with one parent saying that the person that she was, died the day her child did and **"that person didn't know how fiercely you could love somebody"**. Another mother agreed, saying she doesn't think she realised what love was till she had her son, which made it extra hard when he died, but feels that in some way this reminds her to love life. There can be many responses to this realisation of intense love though. Another mother reflected that loving another baby is hard to think about for her as she wonders whether she has enough love in her to love

another child.

Yet another parent identified that the love for her child was the only thing that sustained her in her changed life, and that for her the conscious choice to keep going everyday was crucial. Like many other grieving parents, she eventually utilised a grief counsellor instead of friends and family, understanding that it's not her friends and families' fault that they aren't trained. She is now able to have contact with other children in her community and is finding pleasure in this, reflecting that this would have been difficult two years ago. She often worries about future dates and events but reminds herself to just **"worry about it when it happens"**.

Parents in the group talked about how they deal with **"triggers"** which intensify grief and distress. One parent (ten year bereaved mother) reflected that people in her life have started to **"step up"** to what she needs to help her with these triggers. Another mother bereaved some time ago also discussed that, though there are many exhausting triggers which one cannot help but react to, she can now be **"okay"** that they come and go.

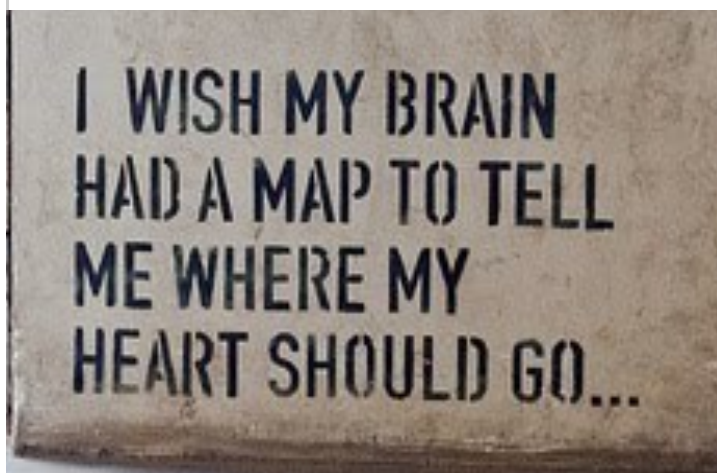
Some parents spoke of the importance of setting the scene as much as possible to avoid being distressed at difficult events, and being prepared. The group

acknowledged, however, that you can't always have everything controlled; no matter how hard you try or how much work you have done a situation may set you back. Those who have been bereaved for a number of years advised not to be too hard on yourself at these times, which can make you feel like you've been taken back a couple of years in that moment. **"You just have to go with it; I used to think I had to have control of it, but you just have to be okay with it"**.

Group participants discussed that not only who you are, but what you do and how you manage to invest in life, changes so significantly when your child dies. As one father said when speaking of how things change as time proceeds, sometime down the track though pain is still there **"it is easier to get up in the morning. We learn to function in this new world"**.

Thanks to all the parents who shared together their thoughts and experiences around this complex topic.

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# *Straight from the Heart*



**Thanks to Sarah and Oliver – Henry's mum and brother for their contribution**

Grief can never lose you  
Heartbroken is grief  
You're jealous of others  
You feel terror and fear  
True happiness is extremely rare  
Grief changes you forever  
Grief doesn't get smaller you get bigger  
Sadness is forever  
Treasure your loved ones  
That's grief  
grief.

By Oliver Barrett (11y.o)



## *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  
email address.\****

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

**Thursday 19th July  
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:

***“Navigating anger and other difficult emotions –  
the many facets of grief”***

Please join us in July

*The newsletter is always a team effort.  
Thank you to Robyn Clark for facilitating, guiding the group discussion and writing the newsletter  
and to Soraya McGartland for scribing parents' statements.  
Also to 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***

