

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER JULY 2018



Welcome to the July 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.

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

There was much engagement in this month's topic. From the outset of the group when parents were introducing themselves, their child and the particularities of their situation, they began also to share their experiences of anger in grieving. These stories and sharing of lived experience were very moving and offered a richness of varied perspectives to group members at different points of their grief, on how to navigate the intense emotions grief brings.

One of the first dilemmas brought up was the struggle of who or what to blame for one's loss.



A father pointed out that not having anyone to **“blame”** leads to being **“angry at the world”**, being now on this journey of grief forever. Others agreed: **“I was just angry, not at anyone, just angry”**. Others spoke about **“channelling”** their anger towards others, for instance at parents who would complain about their kids (who are still alive). Another parent talked about it as an anger without logic, directed to everyone else.

The anger comes with questions such as **“Why us, why him? Did we do something wrong?”** One mother whose child died eight

years ago stated that although the anger now is not the same as it was then, the **"why"** questions remain. However she stated that the anger has evolved over time to being more like **"frustration"** now. Whilst she was angry at everyone in the beginning, it does not feel like an issue anymore as it is much less intense as time goes on. Several of those whose child died some years ago were able to reflect that it is **"not the same anger now as it was initially"**.

Another mother bereaved ten years ago spoke about being angry with the world for a long time but agreed it has changed, the feeling now being more one of **"impatience"** with people. She stated the grief



had an impact on her capacity for compassion: **"My compassion for other people changed - my compassion reduced"**. However her compassion for **"families and children who are struggling"** has continued.

Following on from this idea of diminishing compassion, a couple of group members spoke about a sense of **"hardening"** that hospitalisation as well as bereavement brings. **"It hardens you, living with a sick child and navigating the hospital system - you just have to 'suck it up'"**.

One father spoke of how he hardened up towards others around their response to him processing grief. He said that for him the biggest challenge was the expectations of others and how they could support him and his wife. However he has felt recently a softening in himself towards his parents and siblings. It has been an ongoing process of starting to share more with those closest to him. **"I've just welcomed family back into my life. The more I give the more I receive but it's hard. I'm doing**

the best I can. But some days are shit, tragic and then there are good days, good minutes"

He has tried to stop **"deflecting"** his experience, describing a recent realisation

that he and those close to him **"can do this together"**.

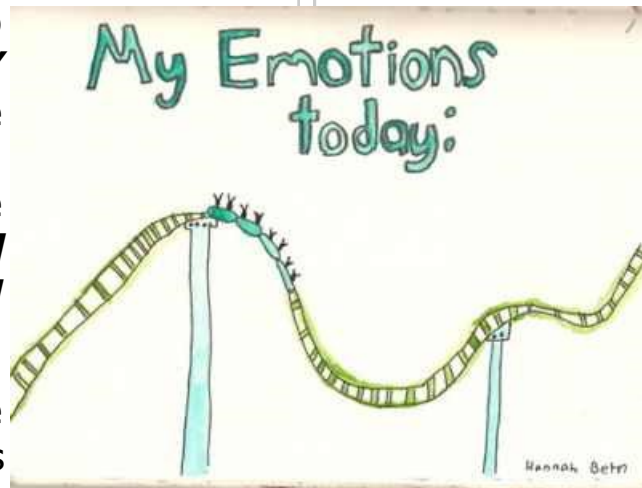
One mother stated she was initially angry at everyone, feeling that her son was cheated of a life he deserved, with all options taken away. She feels that anger still is very present. Approaching the second year anniversary she expects she will be **"disappointed, angry or upset by others"**. Several group participants expressed the pressure they felt from others to be consistent in their grieving process, whereas their emotional state was very changeable. **"Friends think the**

grieving is linear if I'm having a good day", said one parent. Another mother worries that if she is having a good day, her family: ***"just expect that's where I'll remain"***. She wonders why they need to be reminded that she lost her child just because she looks happy one day, or laughed last time she saw them. ***"Maybe next time I won't be so talkative - but I don't want to be like that. I should be allowed to be angry or frustrated"***. In this way she voiced the dilemma of feeling guarded with emotions and not wanting to be ***"too happy"*** in case people disregard her grief, but also feeling she ***"should be allowed to laugh out loud when I want"***.

Some mothers spoke about how relationships with their in-laws had been particularly strained since their child's death. ***"I was angry at them, thinking we are telling you what we need and you cannot even listen to that"***. Sometimes it feels too hard to explain to people what you need: ***"I was just too exhausted to tell them they made me angry, or what I need. When some days just reminding myself to breathe is hard"***. This mother stated her own folks ***"got it"*** because they saw them on a day to day basis, ***"saw the house, saw our body language. My in-laws didn't have***

that because they weren't present to see us every day". Her own parents could ***"receive"*** her anger and she could be ***"blunt"*** with them. However even with her own parents she thought she had presented on the outside as ***"ok"***, only much later realising that actually they *could* see she wasn't coping, that was why they dropped off meals, etc. Another mother stated her relationship with her in-laws has never really recovered after her child's death, describing the relationship as ***"civil, not close but superficial"***.

Parents spoke about how they navigate their investment in new children whilst sometimes feeling guilt for what was lost for the child who died. ***"I was tired still struggling with that guilt of the lost opportunity with [child who died]"***. She was often reminded of it with the sibling when he would do ***"something his brother never got to do. There is always someone missing who never got to do any of these things like ride a bike"***. The feeling at these moments is of exhaustion as one lives two lives, valuing the sibling but also thinking about what your other child could and couldn't do. This is further exacerbated by another fact group members also mentioned - that the dead child



often lives on a pedestal as a "perfect child".

Some felt that their child's death significantly changed them as parents. One father described that prior to his son's death he was an **"easy laid back father - but after (with his other child), I turned into overprotective father attempting to eliminate all risk. I changed as a person in a six week period of my child being born and him dying"**.

Another mother identified no anger but **"just sadness"** that her daughter has gone. It is **"just shit to lose a child"**, she said, and this was echoed by others in the group.

Some parents spoke about the importance of allowing themselves to be where they are with their emotions without trying to cover this over. One mother stated **"grief is a whole lot of afflictive emotions and sensations"**. She felt that understanding something of "stages of grief" helped her, **"helped normalise my experience"**. Similar to other parents, she experiences **"anger towards everyone else. I can't put logic to it; I'm just angry. These are**



spontaneous emotions. I allow myself to be angry and jealous of my friends who have healthy babies. I have no expectations of myself not to feel that intensity, I'm not pretending to be happy". One father talked about feeling he had a sign on him identifying that he was a grieving parent. This father had never identified himself previously as an angry person and had questioned **"have I been suppressing this anger? I had a new identity. It affected relationships. Nothing felt normal, your whole life is not normal"**. For him there was no sense of normalisation around stages of grief.

For some reconnecting with family or friends one has felt estranged from, signals a different part of the grief journey. One father spoke of his gradual reconnection with his brother following the death of his child. He had been a loving and very involved uncle of his three nephews, but following the death of his own child he found it very difficult to visit. His brother struggled to talk with him about this: **"I had to instigate the conversation of 'I need you. This is what I'm going through. This is what I need. Let's talk about it so there is open communication'. I was craving for him to be there for me. The bridge would have lengthened if I didn't attempt to connect"**.

For some the intensity and drive of their anger necessitates a direction,

a way to utilise its power. One mother described that her anger felt like a strength: **"It is something so overwhelming I had to let it out. It was a journey getting the anger as a force and working out how to use this well. I was trying to find a target"**. This mother turned her anger to advocacy, writing to various people including the health commissioner, which made her feel stronger as she contributed to the securing of two childcare places for families with a child in hospital, at the private childcare centre on site. Although she felt **"guilty for saying angry words during my grieving process, if I hadn't used the storm I wouldn't have got that"**.

A father spoke about his anger **"at the grand vision of what my perfect life was going to be. Suddenly we were in free fall, day after day, living flight or fright. We were struggling for normality but there is none. It's just trauma; the floor was falling underneath us"**. In this context he realises anger **"couldn't hold him"**. He described that it turned into self-loathing, and then turned back onto others. He told the group that prolonging the hurt and the pain made him realise anger doesn't help. He stated the anger he felt was having a physiological affect and making him sick. He was putting on



weight, withdrawing from society, **"living in the dark house, the pain house"**. As he started to release the anger he also **"released the aches and pains, the accelerated heart rate"**. He described not wanting anger to drive his daily activities any more, and thinking **"Do I want to be this angry person? This is not the person I want to become"**. A mother agreed: **"When I'm angry at others it doesn't affect them, but holding onto anger doesn't help me"**.

One mother spoke of the ways she had tried to escape her anger: **"We indulge it or replace it or avoid it, worrying how one could be a 'good person' yet be so angry. Strategies previously used to process anger didn't work, it all fell apart. You have to go through it, allow yourself to be angry. Then I could see what others are going through, the loss of grandchild, son"**. She described that when overwhelmed with anger she felt as if she was in the valley, not able to see anyone else, then suddenly was **"on top of the mountain"**, able to see others

again, **"telling people how they can support me"**. She also identified as beneficial that she knows very deeply how to support others to get through their pain. She sees this ability as a gift from her son. **"He has given me a gift to connect with others who have such great loss in their lives, and I can support them through this. He just keeps supporting me to give more"**.

Another mother asked the group: **"When you are feeling angry if you have no one to direct it at how do you get through it? I need to let others know when they piss me off"**. At times she feels excluded around social events; whether or not she wants to go it would be nice to be given an option. Sometimes bereaved parents try to say what they need but people **"can't deliver"** This mother identified however that the anger and frustration is **"slowly seeping away - it's not as intense. The anger has changed. I am able to understand others do not have insight or are not listening. Jealous anger gets me the most... I look at strangers and families with their adorable baby in the street, and it's not fair"**. She identified her pride about her son and how when she talks about him in her memory she wants acknowledgement of this. **"Call me a mum"**.

One father described a **"lightbulb moment"** when he met another

bereaved parent at a conference: **"he seemed so positive and I thought how do you give out that persona? His advice was you can't change the event. But you can change the story; I can change how I deal with the event, change the thoughts. I see light love happiness joy and compassion and I still have pain and suffering, but I can be there for others now. There has been a dramatic change in our relationship as parents and friends. We take two steps forward, three steps back. Anniversaries are always hard. I'm over what others think of me, all I can do is focus on my story, my family and my children, I don't need validation from others. I don't call it anger; I call it a darkness phase characterised by sadness and loneliness - it's just part of my story"**.

At the end of the group this parent thanked the group participants for providing a space in which all these complex emotional experiences can be shared, that although the pain of their loss continues to be carried, being able to share with others in this way is invaluable.

Thanks to all for a candid and rich group discussion.



Straight from the Heart



Thanks to Robyn Sell for her contribution.

Where Did the Old Me Go?

*I really do not care,
For when I read this topic, it stopped me in my track.*

*I found myself just sitting, not thinking,
A mental block, a blank stare.*

*Then snap! I blinked, I took a breath,
And then I thought, there is no looking back.*

*Who am I now & how do I let people know?
I am who I am, may not be the same as yesterday,
I'm still working it out, I'm still finding my way.*

*It's not up to me, it's not my job to let other people know,
I have my work cut out, a long way still to go.*

*For I am a grieving Mother and the journey is real slow,
The hardest job ever known with no preparation put in place.*

*Even an attempt to let others know is a waste of time,
For they could not imagine what is in my own head space.*

*The past has been and gone, but the power it has is crippling at times,
We have the future ahead of us, and I'm sure it will be fine.*

*The one and only thing I'm sure of is I made it here somehow,
The only thing I do believe in: We only own the now.*

Robyn Sell 16/6/18

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 16th August
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:

***“Stories: our children’s stories and our own as
we navigate our changed lives”***

We invite you to bring along an item that is of significance to your child's story.

Please join us in August

*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 Carlee Maggs from Holmesglen TAFE for mailing assistance & to Jenny Jelic
for ensuring the newsletter is typed, formatted, collated and distributed to interested people.*

Social Work Department, RCH

