

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER FEBRUARY 2020



Welcome to the February 2020 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.

### MOVING FROM WHAT COULD HAVE BEEN TO WHAT IS – ADJUSTING TO LIFE WITHOUT YOUR CHILD.

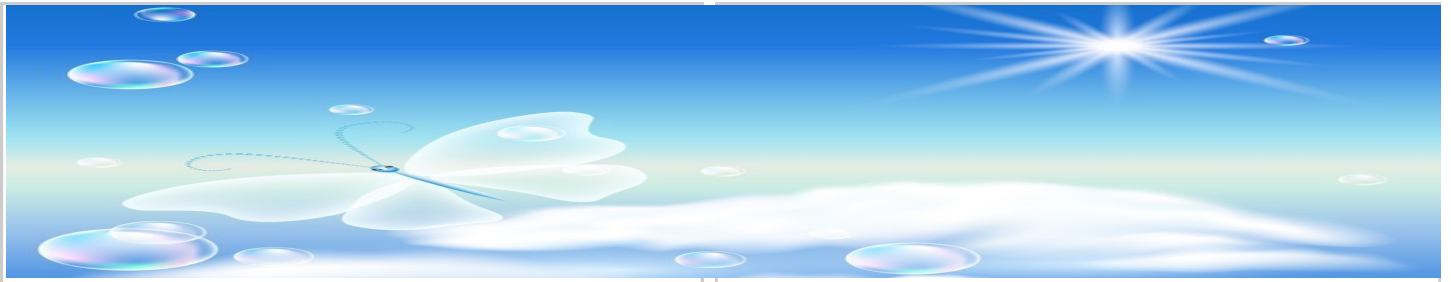
When a child dies, grief encompasses not only the loss of the child who was with you, but also the loss of who they could have become, their potentiality in life. This brings a particular complexity to how bereaved parents adjust to thinking and feeling about life without their child. In February nine bereaved parents came to think about the “what if’s” and “what is” together and share their experiences and perspectives on this topic.

A number of participants had either recently had an anniversary to navigate, or had one approaching. Some had just experienced the first anniversaries of their child’s death, and others were anticipating it and wondering

how they would get through it. Other group participants continue to navigate these days, years down the track, including one mother who had just had the 10<sup>th</sup> anniversary of her child’s death. Parents spoke about the different emotions these significant days evoke, and how they manage to deal with them.

A father, introducing himself and telling us about his 8 year old son who died, stated that his son would have been 10 years old the week before, also their daughter just turned five, which brings up difficult thoughts and feelings around the absent child who is not growing older. A mother linked this with the “what ifs”, describing the “little things” that come up around significant milestones making





her wonder what her child would have looked like “had our story been different”. Another mother talked about how she baked cookies to take to the school with the siblings for a celebration and how this feels hard because “celebrations often remind you that something is missing”. Several parents agreed that they feel frustration, distress and some guilt at not being fully present for the “good times” with their other children. However, trying to ignore feelings of grief and sorrow can be counterproductive, as one mother expressed: “If I push it away or block it, I will fall into a heap”.

For those that have had other children, caring for them and celebrating their milestones can evoke mixed feelings. For instance, when a sibling starts kinder or school, the thoughts of your child who never got to this point are very hard. And yet, some parents stated their other children can give them a reason to “live life, get up in the morning”, and for others a sibling can also remind them of the child who has died: “I see him in his brother”. One mother spoke about being awfully worried that her son will feel her expectations as a “baggage or burden”, as he is her “lifeline”. Others spoke about the fact that, if their missing sibling were still here, the living children would also be different.

Some parents asked about ideas for celebrating or marking anniversaries, and participants shared the different ways they have done this. One family went to the zoo which was the last place where the family spent time all together. The mother remi-

nised about this time and spoke of the importance to the family of “keeping up the tradition”. Another mother talked about how her family go to McDonalds or for a play at the park near RCH. The old helipad near there has special significance and is a place where they can remember the departed child. Another mother shared that their family spends anniversaries at the beach, despite and partly because of the fact her son never got to go there. She finds it “cathartic” that the family goes to the ocean at this time, and it is an important ritual for the immediate family, not others. There is often a “pressure for things to be right” around anniversaries and some described the lead up being “worse than the actual day”.

Some months can be particularly difficult when the date of your child’s death coincides with other losses in your life. One mother spoke of her struggles when her father died, feeling badly that “the loss of my parent felt harder than the loss of my child”. There was acknowledgment that parents play an enormous part in one’s sense of self and this mother expressed “I am who I am because of them”. Their death can leave one feeling “like an adult orphan”. Some group discussion followed regarding the place of grandparents, and how losing your own parent also can feel like some of the memories of your child are lost with them.

One mother found the second year after her child’s death much harder than the first. Many things had changed in their lives, the focus had

shifted to her sick mother, and as the anniversary approached she also became unwell. “First year I was in this fog. Second year, I was physically sick. By the second year society expects you to be back to your normal self”. For this mother, living in “what could have been” is what has helped her and her husband to get through. She described the “what could have been” as an acknowledgement of her son’s presence in their lives. Thinking about doing things differently can be upsetting: “If I forget to do one tiny thing, it feels like I’m losing grip. I want to do it forever because I don’t want to lose it (connection with child)”. However, in discussion with the group this mother described how there have been subtle changes around how things happen over time. Having previously wanted as many people as possible to come to rituals and events honouring her child, now she feels sustained by a smaller group of people who want to be there and who are able to express their love for her and her child – “quality over quantity” – having those who bring their love to celebrate “as opposed to more people, less love”. In addition, very large anniversaries or birthdays can be “exhausting” and hard to navigate given feelings can change through the event. Several parents agreed that it was easier to have only immediate family at anniversaries and significant days, and all agreed that it was important to have those who better understand you, whoever they are, around you at these times, rather than hoping a large group of people will be there and understand what you need.

The group discussion moved to a reflection on a strange feeling that many parents felt, an emotion or a memory that feels at odds with reality. One couple were approaching the first anniversary of their daughter’s death, and her

mother described an intense thought/feeling “like she’s on holiday and will come back”. Another couple, commenting that their child would have been five years old this year, described this as “strange and unfamiliar”. Yet another described having moments of realising as if for the first time: “He’s actually gone and he’s not coming back”. She spoke of the sadness in explaining to siblings as they get older why they “visit” the hospital.

Another stated: “A whole decade has gone past, but it doesn’t seem like time has gone by that fast”. Occasionally, even ten years on, she wonders “Did that actually happen”? In all the photos of her son in their family home, he is a baby, yet there is “no evidence in the house of the ten year old boy that he would have been”. Others agreed that they can still feel their child in their house: “I know he’s not but I still feel him everywhere” yet there is a disjunction between how they remember their child and how their child would actually be if still here. One parent described it as “trying to live in two different places at once”, and that they now “know what it is like to feel happy and sad at the same time”.

Another shared the feeling that: “My life moves forward but part of me is still there. Flashbacks of insignificant moments pop up randomly. I don’t feel that where I am is reality”. However one father expressed that he finds that experience comforting and actually fears forgetting “every little detail”. “I’m rewinding like a tape because I don’t want to lose it. I don’t want others to forget him. I think the world of him, how could anyone forget him?”

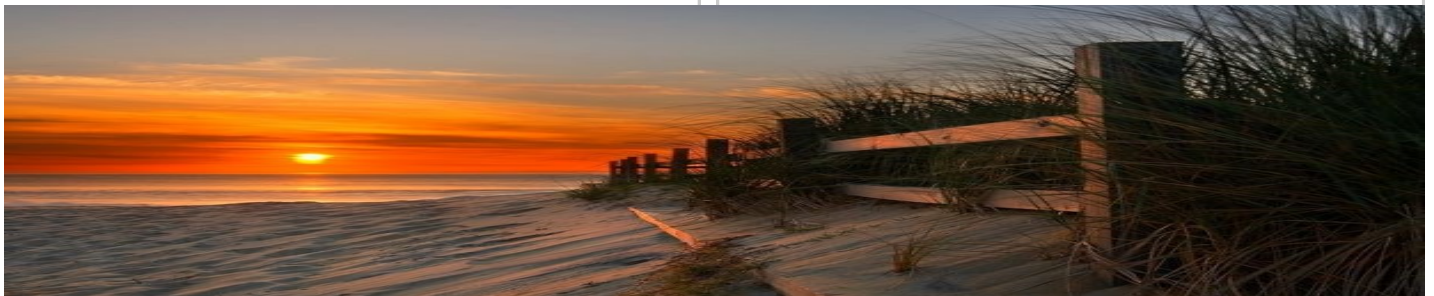
Publicly acknowledging your child as still part of your family though no longer physically present, is something that is often talked about in the group. It is part of holding that tension between what was and what is

now, and honouring your child in that process. In this group once again the dilemma of how to do this was raised, with one mother asking what parents do if they are asked if they have a child or how many children they have. There was a lot of discussion about this, with people describing how it depends on different factors such as who is asking, whether you know them, how you're feeling on the day and whether you want to have the conversation or not.

One father says "I have a son; he passed away", or "Yes, I have a son & he was ten months old". Another said it depends who asks. He "filters" according to context and circumstance. It's not always clear cut and sometimes at work or in other public settings it is too hard to go into detail about the circumstances of your child's life and death. One parent described feeling guilty for at

prove this to some people. Another mother stated that sometimes she didn't want to speak of her child who died as there is the impulse to "keep him to myself". However it was also raised that sharing grief experiences can, at best, be "positive", rather than negative. This can be affected a lot by the quality of others' responses to sharing your loss. Some people can be insensitive, and others simply uncomfortably unsure what to say. In relation to this some of those who have been bereaved for a longer time were able to describe how grief does evolve over time. One mother shared that although she had struggled at the time of her child's death with what was said to her, over time she feels she can better manage people's responses.

Though at times parents can feel defensive in regard to their deceased child, many spoke of



times saying they don't have kids to "save face" at work. Boundaries around not delving into the story are at times important but he doesn't want to lose his sense of self and of his child. Many agreed that it is "painful as if I stabbed myself in my own chest to say I don't have a child".

One parent commented that it's really hard when you don't have living children, to say you have a child and you are a parent", as often there follow questions about where your child is. One mother talked about the importance of still being recognised as a parent, to have it "acknowledged that I was a mum" and still sometimes feels she has to

being sustained by the memories that others share: "The people who matter still remember". Group participants shared their reflections and thoughts on the place of memories in their life. One parent whose child had been only briefly in this life, wondered: "how can something so brief be remembered"? Some memories can also be incredibly painful and stretch our capacities to make sense of things. One parent talked about the memory of having had to make "horrendous" end of life decisions, yet knowing they made the right choice, with their child's best interests at heart. She wondered "how could something right feel so wrong?"

Parents spoke about the people in their lives who remember their child, who can share memories. Often this is with other family members including siblings. Some parents spoke of fears that a sibling would “forget” their brother or sister. Many talked of how they tell their child’s story to siblings as they grow older, but also their dilemma of how to do this without “forcing” memories onto them. It was acknowledged that in many cases memories for siblings are built from the narratives told to them by parents, and that their perspectives may be different or may change. The worry about whether memories are really “true” in this sense, particularly for siblings, came up. The facilitator commented that maybe people always remember through their own particular way of loving, that memories are coloured by that love. There was also a discussion about the ways in which memories are triggered. Many parents talked about how their memories returned in relation to smells, a sudden memory which was thought long gone, triggered by a new laundry washing liquid, for instance, or the smell of soap which brought back the memory for one mother of showering with her child.

A father returned us to the “what if” question: “You think of what it would be like now, but it’s hard to remember what he was like”. Parents spoke about seeing kids

in their son’s year level and imagining what *their* child might have been like. One described this as the “bitter sweet of what would have been”. Yet others spoke about how the reality would be very different to the “dream” one might have had when pregnant. Some parents spoke about their imaginings, when watching other children, of their child walking or reaching other milestones, whilst simultaneously realising that their child, if alive, may not have been walking at all, may have been in a wheelchair or in other ways affected by the condition they died of. This linked back with the question of reality and unreality, memories and wishes, what if and what is and how parents adjust to the strangeness of competing perspectives as time marches on. One father commented that if what happened to his child had not happened, he would be a different person: “If I didn’t go through this I would be a whole different person with a whole new life”. He described it as a “sliding door”.

A mother told the group that she had had an experience at a playground where there was a mother with two children, one the age her child who died would now be, and one the age of her other child (these two played together). This coincidence of the children’s ages gave her a window into “what it might have looked like”, watching the siblings play together. In a way this was a “what if” which she found sustaining.

Parents had a range of different responses to encounters with other babies, children or



pregnant women. Some mothers spoke of the difficulty of having been pregnant at the same time as other women and having to be around them post their own loss. One mother talked about being comforted by other babies, whilst another found such contact very anxiety provoking, particularly when she found out her neighbour was pregnant and had to see the child once born. Talking with the new mother, she felt the pressure to “prove” herself as a “real mum”. However she identified that as time goes on she feels less need to prove herself: “although I’m grieving and mourning, the trust I have in my self is back again”.

One mother identified that some of how you feel as a bereaved parent changes according to the way others approach you. She has experienced times over the years when other parents avoid her and keep their children at a distance. In contrast to this, when there is a transparency and acknowledgement of your loss, a respect for your boundaries “without casting judgement”, it can transform seemingly difficult encounters. She described that at a gathering a woman she knew who had an infant had openly admitted “I don’t know what to do” and asked her what she would like, then letting her hold her baby for two hours, which was a treasured experience for her.

As parents spoke in the group of the richness and complexity of their thoughts, wishes, imaginings and memories, it became clear that the movement from the “what if” to the “what is” is not linear, rather that these two perspectives often come to be held in mind simultaneously. How this is navigated in each parent’s life is particular to each family,

but can provide strength to other bereaved parents when put into words and shared..





Many thanks  
to the parents  
who shared  
their stories, experiences  
and wisdom with us  
and allowed us to use their  
stories to write  
this newsletter.

## *Our letter box is Waiting!*



Contributions such as responses and reflections on the groups' themes, poems, letters, songs, reviews of books that you may have found helpful, 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 March 2020  
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:

**Beliefs, philosophies and worldviews: how they change....**

**Please Join us in March 2020**

*The newsletter is always a team effort.  
Thank you to Robyn Clark for facilitating the group discussion  
And writing the newsletter. Thank you to  
Celeste Luciani for scribing parents' statements.  
Also to Marina Puljic for her assistance to ensuring the  
newsletter is typed, formatted, collated and distributed  
to interested people.*

