

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER MAY 2022



“Living and Remembering”.

May’s bereavement support group was attended by seven participants. For many of those attending the group, May is a very difficult month. In our customary introductions to participants and sharing around their child’s history, several parents spoke with heaviness of this month being particularly difficult, with several recent anniversaries of their children’s passing, as well as Mothers’ day which often evokes and intensifies their sense of loss.

One mother had been navigating



the very painful 10th anniversary of her daughter’s sudden traumatic death. She described Mother’s Day as being very difficult every year, though there is never one date that is difficult but rather multiple dates of remembrance which can be “**triggering**”. A couple attending the group had recently navigated the anniversary of their son’s death. They described clear memories of medical processes and the dates when different procedures occurred, and alluded to the strangeness of time passing since their lives changed four years ago. A mother spoke of

her daughter who died more than ten years ago after two years of being **“in and out of hospital”**. Another mother, whose child was born around the same time, had had a similar experience and stated she also had a very clear recall of all the dates and all the procedures. A number of parents spoke about the difficult decision to turn off life support machines: **“What was a heartbreaking decision for us, was only the fair thing to do for him”**. One spoke of the pain of also having to make a decision about donating her daughter’s organs when at that time of acute loss all she really wanted was an organ that could keep her own child alive.

One couple spoke of the death of two children in the space of six years, both dying around their first birthday. May is once again a particularly difficult month for this couple, with the children’s birthdays and time of death close together.

Stroebe and Shut in the mid 1990s spoke about the **“dual process”** that bereaved people often go through, oscillating between a **“loss oriented”** focus, confronting the grief head-on in all its intensity, and at other times a **“restoration-oriented”** focus, where one is more able to attend to life tasks, changes and relationships. This was a challenge to older ideas about grief, and acknowledges that it is not linear and that people

move back and forth between these different states in their own way and time as they navigate their grief. Our topic for the night **“Living and Remembering”**, reflected these different lenses, however with the sense of how difficult it is to sustain a restoration or life oriented focus at a time when you are encountering anniversaries and other triggers of remembrance of traumatic times.

One mother in her introductions commented that **“Life goes on for all of us without our children”** and **“we are stronger people for it”**. She spoke about finding space in the duties of life for remembrance, and holding dates in her head to do this. **“I talk about [child] every day, to anyone who will listen, when its appropriate”**.

With this the group began speaking to the topic of **“Living and Remembering”**.

A mother expressed that parents live with the loss of their child **“every single day”**, and that this is a many faceted loss including the loss of future possibilities and milestones for their child: **“We live with the *fact* of what we have lost, but also the *future* of what we have lost.”** She described how, when she sees the friends of her daughter, now grown into their 20s, **“it’s never going to add up in my head”**. Other parents in the group expressed similar feelings.

Parents spoke about how their children who died **“continue to live through the memories”**, the memories coming forward with the parents in their life and becoming a part of it **“as if he is still living with us”** said one father. Their son becomes present through their memories.

His mother added however that life events also can be a trigger for grief and sadness, confiding that with school photos being undertaken with siblings the next day, the sibling photos will be incomplete. **“We used to take these things for granted”**, she reflected. This reflection led to some discussion about the importance of photos in holding memories for the living. Some group participants described family photos of the **“grandkids”** with all grandchildren present in the photo including those lost. Parents discussed that photos can be used together with talking, to bring your child who died into conversation.

The group discussed the impacts of their child’s death on family relationships, and how the death can be acknowledged in different ways with different family members. Sometimes knowing how to keep your child present to their living siblings can be tricky. Siblings have to find their own way of **“remembering”**, even if they did not know their sibling in their life

– memories can be created for those that may not have had the opportunity to meet their sibling. One mother spoke about how her two younger healthy children know about their brother and have a relationship with him.

Some parents spoke about how their living children often ask questions out of the blue about their lost sibling, one parent acknowledging **“I don’t always have the answer to the questions.”** It was reflected that being available and giving permission for questions is perhaps more important than having the answers per se. One mother identified that a sibling death can change a child’s conceptualisation of death, making it more concrete and giving them a capacity for compassion: **“It makes them more compassionate to their friends”**.

Some group participants spoke about how grief had a lot of anger mixed in with it in the early years. One mother described how she looked (and still looks) for signs that her son is around. She has created a memorial shelf in the family home which the siblings are able to add to.

The death of a child can also bring forth hidden stories from friends, including stories of other members of extended family that are no longer present.

One mother spoke about how her

grief is impacted by the recurring trauma she experiences around the circumstances of her daughter's death. **"It's like a movie that goes on in your head"**, she said. **"I don't see the movie every single day, but at key dates of remembrance and anniversaries, there are very clear flash backs to the events that occurred around the time of her death. It was such a traumatic event"**. Other parents spoke of different experiences, where the death was anticipated due to chronic illness or disability, some stating that in a way this prolonged the start of the grieving process.

There was a lot of discussion between parents about the multifaceted nature of memories. Not all take you back to the trauma of the loss. One parent commented that the **"memories that are on repeat in my head, are more often the happy ones"**. **"I quite regularly think about what was I doing on this date while he was going through treatment"**. Another kept a journal at the time and stated that when key days of the experience come back she can still feel **"sick"**, however on other days her recall is not so clear. Over the years, she said, the pain and distress of her grief response has diminished, and although some key dates are difficult, for her the anniversary is not necessarily one of those days, and she also has a lot of **"beautiful memories"** from that day. Another parent whose child died many years ago

commented: **"I feel I am able to cope with things better now"**.

For some parents the lead up to the date is **"worse than the day itself"**, bring a kind of anticipatory **"melancholy"**. One described that they feel the loss most strongly in family events when **"he should be there"**. **"There is always someone missing"**. Another commented that in having one of the cousins in the car with the siblings she suddenly thought **"that's what having three kids in the car would be like"**. Events like the Good Friday appeal can bring varied emotions, evoking **"the idea that hospitals are meant to save kids. Now I just get really cranky because they didn't save [our] child. They don't save every child"**. One mother's daughter passed away just before the Good Friday Appeal, and had previously been intended to be the **"face"** of the appeal. It was distressing that the decision not to go ahead with using her image was made without first finding out what the parents would prefer.

Parents identified that sadness does not always come when you are anticipating it, but at all sorts of times out of the blue, one commenting that it had suddenly struck her: **"I don't know what his name would look like in his own handwriting"**. This is a version of the sense of loss for what **"could have been"**. Another described that **"the years roll on,**

but you begin to cope with it better". She captured something of the changing states of grief by recalling a fellow group participant's words from nine years ago: **"there's a pebble in your pocket, and it's always there, but sometimes it feels like it's a rock."**

The discussion focused for a time on ways of remembering your child. One parent commented that these newsletters can be a way of remembering. **"Remembering and living" has its "ups and downs"**. Another noted that bitter memories **"stick with you"**, and though the bitterness has softened over time, it never completely goes away. **"I even dread driving on that road" (to the hospital). "Even walking into the building was not a pleasant memory (when coming to the parent bereavement group)"**.

One mother stated **"We don't try to recreate memories,"** but often ponders the fact that siblings forge a pathway that may have been similar to what her other child would have done, acknowledging that the parental influences are the same. The comment was made that **"What if's..."** can be both positive and negative - negative when they turn into rumination on things that should have been done differently, but also positive at times as a form of thinking about what your child would have been like, what they might have done.

One father stated that **"you've got to focus your energy on the here and now, and keep the memories alive."** Parents and families do this in different ways, and often surviving siblings are a part of this. Some parents described how they visualise their child in heaven in the present time. One said that the siblings also describe their brother who died in the present tense, and **"I worry about the time they no longer refer to him [in this way]. When she [sister] loses her innocence, will he lose his presence"?** Another stated **"it just evolves with time"**. **"My kids switch between past and present tense all the time"**. Another mused that **"siblings build pictures through everyone's memories"**.

There followed some discussion of how rituals can be important, for instance, regularly laying flowers at a memorial, cutting a cake for the no longer present child, with their siblings, or singing songs for your child.

Parents were asked: **"Who holds you when the memories are really hard"?**

Some felt fortunate and extremely supported, others less so but many identified some important others in their life who can be present with them during very hard times:

"My family and friends. They send mementos on anniversaries to show they are thinking of them, or send things outside of those times to

show that they are remembered”.

“My mum – she is who I connect with”.

“My best friend – my cousin – we grew up together. She also remembers those dates, and checks in with me. She is very good at reading me”.

“Dad – he is the one I am closest to, but he can’t talk about it, ‘because he can’t fix it for you’”.

“Sometimes you grieve differently to your partner – he only remembers it because I’m all over the shop”.

“My sister – since she has had children it has changed her perception of the loss”.

Thanks to all the parents who joined together for this group in the midst of a very difficult period of time, and shared their thoughts, feelings and experiences of both “living and remembering” with each other.

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

The next meeting of the
Family Bereavement Support Evening Group (Via Zoom)

Thursday 16th June 2022 at 7.30pm

Please join us to discuss the topic:

“Understanding Grief”

If you wish to attend this group please
email: Bereavement.Services@rch.org.au



The newsletter is always a team effort.
Thank you to Robyn Clark for facilitating the group discussion and writing the newsletter,
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Social Work Department, RCH



