

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER MAY 2018



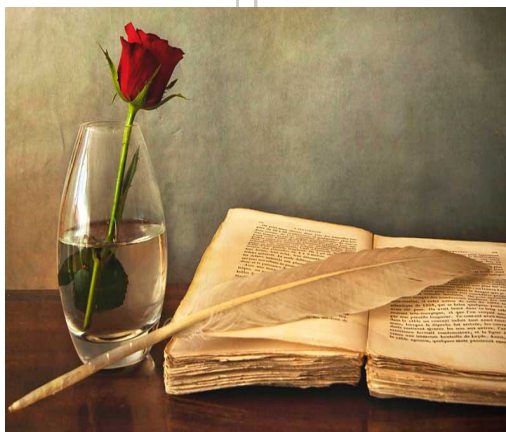
Welcome to the May newsletter of the Family Bereavement Support Programme. We hope that in reading the newsletters and being a part of the groups you will find connection with other parents, support and encouragement to help sustain you as you grieve for your child.

“Grieving and Literature - What have you found that helps?”

In keeping with our usual format we began the group with introductions. Thirteen parents attended the group, some whose child died over ten years ago, and others whose loss was much more recent. Though circumstances are different in each case, the group setting allows parents to speak of their child and what happened to them with others who are able to really listen and empathise given their own experience. In the group people are able to talk as much or as little as they want to. Some parents find it helpful just quietly listening in a space where others have some understanding of what they are going through as a bereaved parent.

The group shared an

extended discussion before addressing the night's topic, as the session fell not long after Mothers' Day and many parents spoke about the day being challenging and how their child's absence had felt more painful at this time. One mother spoke of her feelings of loss at the realisation, when her elder child gave her a card, that she had not received a card in her deceased son's writing (he was too little), and never would in the future. Another mother reflected that although on Mothers' Day there is a lot of acknowledgement of people who have lost mothers, there is a lack of recognition of mothers who have lost a child. She also commented that family members did not mention her loss on the day which was upsetting.





One mother confided that her mother is terminally ill, further complicating feelings on Mothers' Day. She also described how leading up to Mother's day her female family members were talking about the pain of childbirth. This made her think about how this is a normal pain in contrast to the pain you go through when a child dies. She also commented that her family members don't understand the concept of what a future pregnancy would be like for a bereaved mother. She feels pressure from others that she should have another child, or adopt one. Another mother had similar experiences - she has also been told **"you are young, you can have more"** by someone who did not understand how hard it is to overcome the fear to have another child. Yet another mother stated it had felt like a **"quest"** to have another healthy baby, though it was also frightening.

Others also discussed the complex issue of having other children after a child has died, something that can bring so much joy but can also remind you of what you missed out on with the child who died. One parent whose daughter was older when she died, spoke about this as a different sort of grief and a situation where it is not necessarily possible to

embark on having another child. Another mother who has had other children since her son's death, described the feeling that **"the maths never add up"** when you have subsequent children e.g. when they sit down to eat or the siblings are playing - there is always someone missing.

Another couple spoke about two significant anniversaries coming up for them. The twelve month anniversary of their son's death from a rare medical disorder is approaching as is his birthday. They are anticipating that it will be a very tough time and wonder how they will ever be able to accept the reality that their child is gone. This mother discussed how much she cherishes objects that her son made at childcare - though other people may feel such things are small or inconsequential they are treasured possessions to her. Several other parents spoke about anniversaries coming up within the next few months and the dilemma re how to cope with them. A mother who has experienced the 6th year anniversary of her daughter's sudden death spoke about her experience of post-traumatic stress. She also spoke about the very difficult decision she had to make about organ donation, and how going down this path saved other children's lives.

This mother also shared how difficult it was when her son passed the age that her daughter was when she died. Her mother, who attended the group with her, reflected on the tough times around this time of year with anniversaries. Their daughter/granddaughter died at this time and

on Mother's Day each year the family have Chinese food as a ritual, have a laugh and talk about their girl. The grandmother spoke of the importance of having the child in the room on these occasions, e.g. reminders, objects that remind the family of them.

The grandmother spoke about the importance of **"hanging on to each other"** at anniversary times. The facilitator acknowledged the feeling described by many parents over the years that you don't ever really **"get over it"** but rather incorporate it in some way in to your life. In this context **"hanging on to"** both the living in your life, and your memories of, and connection to, your child who died becomes so important.

The topic of how language is used by bereaved parents and by those around them was also discussed. One parent found and still finds using the word "died" really hard. Other parents also discussed feeling that "died" was a really harsh word. One mother stated she uses the word when she feels angry or annoyed. One mother commented that there is a word for orphan and widow but no word designating a bereaved parent of a child. Because of this there is a feeling of being unrepresented.

The grandmother attending also talked about her difficulty in social settings regarding what words to use when asked about the number of grandchildren she has. She wants to always count her granddaughter who is no longer here, but sometimes it feels hard to have to explain the

situation when further questions follow. Others spoke of this being **"like a T intersection"** - choosing left or right in being truthful about the number of children. Over time, some parents feel more comfortable with saying what they need to say and not trying to protect others. This question of how bereaved responses change as time passes is often discussed in various ways in the group, with those who have been bereaved a long time ago sharing their experience of what has helped or hindered them in their grief, with group members for whom the loss is recent and raw.

A couple whose son died after spending his short life in hospital, spoke about a **"different kind of pain"**. They queried whether it is possible that time could heal this. The loss feels incredibly raw to this mother and the father feels nobody at work is really understanding of his loss although they try to be supportive. He stated it can be hard to find motivation to perform tasks or work, as your mind is elsewhere, with your grief. However, trying to focus on a task does give some respite.

Many group participants described being frequently beset by the question **"Why me?"**

Discussion in the group moved to the



topic of the evening with the facilitator asking about what helps in getting you through, and wondering about what literature people had found helpful.

One mother described how she had looked to her local library after her daughter's death and was shocked to find they did not have any resources for bereaved parents and siblings.

Books for children seem to be more commonly accessed and group participants stated that these picture books are just as useful for adults as they are for children.

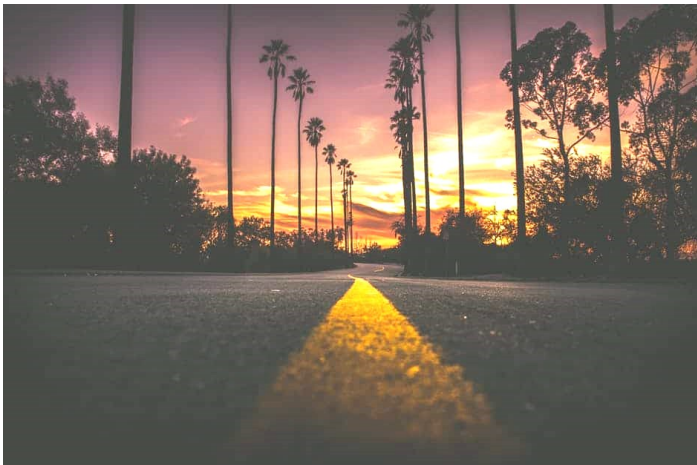
One mother found the children's book *"The Invisible String"* very helpful and described how the story is about feeling connected by an invisible string and tugging on the string connects you to your loved ones. The story helped her to talk with her son about his sister's death. However the concept was complicated for this family as her daughter's heart had been donated, hence her brother was worried about this. The mother explained that the word "heart" also could be understood as referring to his sister's spirit. She read a section of this book to the group. She also spoke about the *"Water Bugs and*

Dragonflies" children's book. In this book it talks about the different stages of life the water bug undergoes as it evolves into a dragonfly, and how as the creature morphs into a dragonfly it is not physically able to return to visit its friends, the water bugs, under the ocean. She said that her son, upon reading this story, felt then that the dragonfly had "betrayed" its friends as it did not return as promised. She said that talking about this, and the dragonfly's inability to return now that it had changed form, had allowed for discussion about the transformation that all animals make over their lifetimes.

Another mother said that although she is an avid reader and reads some blogs, she never looked specifically for grief books. However in the past few years she has come across some books written by other bereaved parents which she has related to.

Several mothers discussed having trouble concentrating and finishing books when they were acutely grieving. One stated that she bought a number of books when her son died however could not bring herself to read them or would get part way through them and then stop. She identified that her **"mind and spirit aren't still enough to concentrate"**. Another mother, who was more recently bereaved, said she borrowed a few books but agreed she felt she did not have the concentration to read them at the moment.

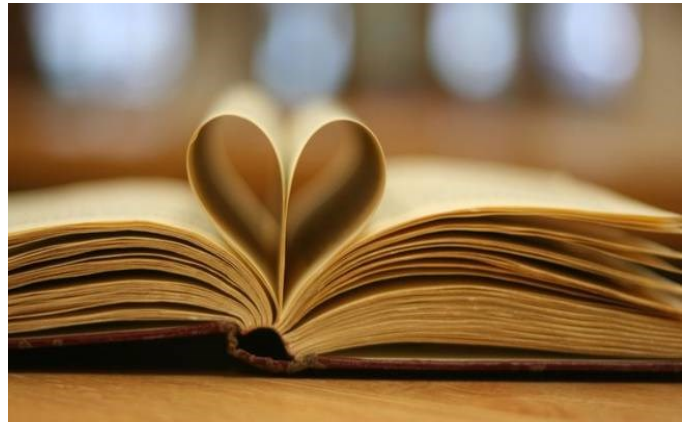
One group participant stated that



although she hasn't really used books on grieving as such, sometimes reading lighter books for distraction has been helpful. When the mind is preoccupied with grief, reading "**something mindless**" can help.

The topic of spirituality in bereavement literature arose. One mother described that although she is not religious she was particularly struck by the ideas in a book concerning heaven, in which a boy who goes through an emergency appendectomy and dies in theatre, subsequently recounts to his parents what he sees in heaven. Other parents knew of this book and one stated there is also a movie based on it. One mother stated that it made her feel better thinking of this idea that children can be ok in whatever world they go to, feeling that "**our love still looks after them wherever they may go**". This feeling of a new interest in spiritual matters is often described by group members as they try to make sense of what has happened to their child and where they are now. The grandmother present in the group on this evening described feeling more religious since her granddaughter died as it allows her to have hope.

One mother goes to the spiritual section of bookshops and has also been to a medium since her daughter died and has found this helpful. She now feels there is "**something out there**" - she states she is "**not religious but the medium has opened [her]**



mind to something a bit bigger".

The facilitator asked whether group members had found reading poetry helpful in their grief, and one mother shared a poem called "*Broken*" - from heavengarden.angel which she shared on Facebook on Mother's Day. Reading and sharing poems on Facebook can help in summing up how you are feeling.

Some parents discussed that they felt more able to write than read. One mother had written in books on many occasions with the intent that her other children would read her writings in the future, but has not continued to do this. Another mother who frequently wrote for her son who died, said she is finding this becoming harder in recent years, and now writes in her journal as much for her second son as well as her first child.

One bereaved mother thought that a journal might be helpful for her to "**vent**", particularly to share it with her partner as another outlet. However she shared that she was fearful about writing about the horrific experience they had at the time of her son's death. She wonders if for her re-reading a journal could be too

traumatic in making her relive it. Another mother commented that the memories of those times can feel like a movie playing in your head as well and **"it is still so vivid"**.

Some parents find that making memory books is a way that family can come together in documenting their memories of the child who is no longer physically with them. In this way special memories are kept over time. This was seen by group participants as a good reading tool for individual families to use to keep their beloved child's spirit present.

One mother told the group that she wrote a blog which had **"all the bad and ugly stuff"** and got a lot of criticism from people who felt it was very morbid – yet other people said they found it very helpful. This mother celebrates all her son's significant dates such as his burial date and monthly birthday date, and writes whenever these different dates occur. She felt the online journal helped so she could say things that she may not have had the courage to say to people to their face, for example when people would say things directly to her which made her feel upset. There followed some discussion about the many insensitive things people say to you when you are grieving the death of your child, when **"all you want is for them to acknowledge how hard it is, give me a hug and say nothing"**. The grandmother in the group reminded us however that people aren't trying to be insensitive when they say things that aren't helpful – they are normally trying to find a way to

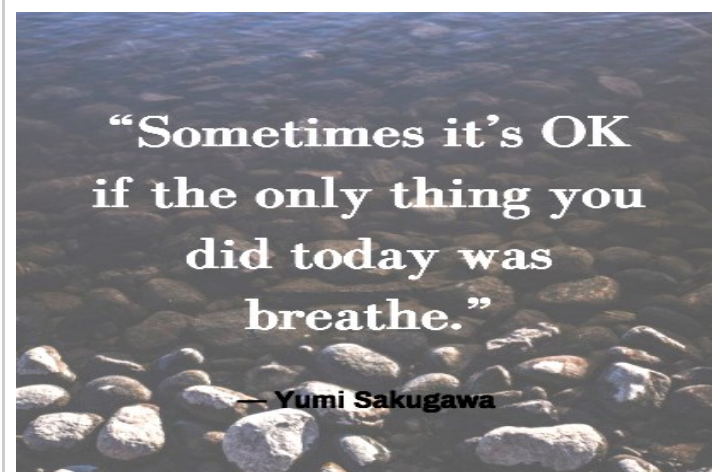
empathise, however misguided their attempts may be.

Discussion in the group moved to the theme of cultural responses to grief and grieving. One mother spoke about the importance in indigenous communities of wailing, dancing and smoke ceremonies etc. She commented that the grief in other cultures, particularly non-Western cultures appears more visible. However sometimes it feels like it's harder to do that public grieving when you lose a child.

In summary, though the topic of the evening was Literature and Grieving, the proximity of Mothers' Day and various other anniversaries gave rise to a number of wide-ranging thoughts and discussion, including not only literature and reading but also the many ways grieving parents seek sustenance through picture books, poetry, blogs, writing, rituals, spirituality and "hanging onto each other" at times of intense grief. Thanks to all who participated.

References:

- Karst, P. (2000). *The Invisible String*. DeVorss Publications, California.
Stickney, D. (2004). *Water Bugs and Dragonflies; Explaining Death to Young Children*. The Pilgrim Press.



Straight from the Heart



Thank you to Kelly Myers mum of Chloe for her contribution.

For Chloe with Love xx

*Would your hair be any longer?
Would your eyes be just as blue?
Would you still be just as sweet
As the young girl that we knew?*

*Would you be enjoying high school?
Would you have made new friends?
Would you still be playing netball?
Would you be into all the trends?*

*Would your team still be North Melbourne?
Your favourite animal – a giraffe?
Would you still love One Direction?
Would little things still make you laugh?*

*Do you have new friends in heaven?
Do they know how loved you are?
Have you been given your angel wings?
Are you still the brightest star?*

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 21st June
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:

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

Please join us in June

The newsletter is always a team effort.

*Thank you to Robyn Clark for facilitating, guiding the group discussion and writing the newsletter
and to Lizzie McNulty for scribing parents' statements.*

*Also to James Megalokakis 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

