

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER APRIL 2018



The Royal
Children's
Hospital
Melbourne

Welcome to the April 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.

“How do we talk to children about death, and about our own grief”

The topic for this group was talking to children about grief and we welcomed a number of parents and friends for the first time as well as parents who are more familiar with the group. The group is a very welcoming space where people are not expected to share more than they are comfortable to share. For some people this means they may say little or nothing while others may feel comfortable to share quite freely. All contributions are valued and listened to and we frequently find that the group contains more wisdom than any literature. This group was no exception as the people in the group shared their questions and concerns, their experiences and their insights. The 10 children represented in the group had lived lives ranging from a few weeks to 13 years. Some had died suddenly and unexpectedly and others had been unwell for varying periods of time and had spent long periods in hospital. Some of these children had siblings before they died and for others siblings have arrived subsequently. One couple are expecting their second child.

For those who did not have siblings, their parents spoke of their experiences and conversations with other children including nieces and nephews and children at school. As the ages of siblings represented in the group ranged from young children to teenagers, parents were interested in how children of all ages talk about and cope with grief.

As a very recently bereaved father was telling us about his experience and about his daughter, he commented on people's expectations of him - **“Everyone says 'be strong'. I feel like saying, 'go away, you don't know how I feel'. That's why I came here, to talk to someone who feels like me”**. Another parent responded, **“I think 'be strong' is one of the most unhelpful comments, and 'at least you have another child' – it's an unrealistic expectation, it's not doable and why should it be? We should be allowed to have a bad day, a bad week. It's okay for the sibling to see us cry”**.

A couple in the group are expecting their second child and raised their concern

about how to explain the death of their first child to his sibling. **"Now we don't know what to say to this little one** (The baby they are expecting). **He went to bed and didn't wake up, how do you say that to a child? We don't want him or her to be afraid of going to bed. We're going to be scared of putting the baby to bed. We don't want him or her to feel that fear"**. They also talked about the difficulty of not knowing what caused their son to die - **"he went to bed healthy and happy and didn't wake up the next morning. No cause has been found... The** (Coroner's) **case will always be open because there is no known cause, we'll never know"**. Another parent told them that it was 5 years before the coroner closed the case regarding their daughter. She said **"It didn't bring closure. I don't think there's ever any closure"**.

Parents who had had one or more child since they had lost their child shared their experiences of talking to these children about their brother or sister. One parent told us that she has a child who is now 3½ years old. **"Before having him I thought, 'how am I going to tell him about his brother'? His brother's room is still there and has his name on the door. He knows his name, he knows he has a brother, but I don't know if he understands"**. She went on to tell us that her father died recently and they also lost their family pet dog. Their child will tell people that his grandfather and his dog are in heaven with his brother. **"We are slowly planting the seed"**. Another parent who now has 2 living children, 7 and 4 years old told us that they have always talked about their first child. She told us, **"we started out saying that he was sick and we slowly added bits of information"**. They answer questions the children have as they arise and feel the younger child knows more than her brother did at her

age as she hears them talking. They also have a number of books about death for children and they may use these when he has questions - **"He calls them 'the dying books'"** She said that her son has been asking more questions about death and how it happens since his great grandparents died. Listening to children and answering their questions honestly as they arise is usually more helpful than feeling you need to sit down and tell them all about what happened at one time.

Sometimes you don't know what children have taken in until you hear them telling someone else. We heard from one parent about a time when she was ordering balloons for her child's birthday. She always includes one special silver balloon for her first child and the children were talking about the balloons for their brother when the lady serving them asked who he was. One of the children answered: **"He was a baby who was born whose heart was sick. He's my brother and he would have been eight"**. His sister then added: **"Yeah, he's my brother and he's dead"**. Their mother also commented that she didn't think that her son understood that his brother was in the cemetery until her father told her that her child had said, **"You know, he is buried there in a box in the ground"**.

Many of the parents commented on the honesty of children. Comments coming from a child may be easier to accept than the same comments from an adult. A parent who is a primary school teacher told us about his first day back at work about 10 weeks after the death of his child. He said he had been dreading the questions when he went back. **"One of the prep children came up and said 'Hi Mr ..., are you still sad?' I said 'I'm always going to be sad'. The child replied, 'Oh, I'm sorry about that' and turned and walked off"**. When his adult neighbour asked him the same question his response was one of rage. What is curiosity and an attempt to understand in a child can be

just plain ignorance and lack of empathy in an adult. This same father told us about a little girl who had lost her brother to cancer, **"She came up to me and just cuddled me, and that was the best reaction I could get"**.

One of the parents in the group said, **"It is much easier to have a conversation with a child than with an adult"**. She shared with us her experience of trying to mark her 30th birthday in a way that included her child. She had decided to go to Fun Fields – she can see this from the cemetery. **"I said to my nephew, 'what am I going to do, I want to do something for my son, how can I incorporate him?' In 2 seconds he said 'just bring his bathers and his photo and put the bathers and the photo on the sunbed.' I just thought, it's so simple"**. In contrast, talking to adults about this was very difficult, as they did not understand what she wanted or did not feel comfortable with this. She followed her nephew's advice and was able to feel that she had included her son in her birthday celebrations.

This parent also told us that they have recently discovered that her mother is terminally ill. She has been in hospital for some time now. When she asked if anyone was going to tell her nieces and nephews that their Nona is going to die she was told they were not going to be told. **"I stopped asking because my sister got shitty with me"**. She told us that although she hasn't been told, her 5 year old niece has said to her 'you know Nonna's going to die'. She worries that her niece knows too much or has too much to worry about, however it is likely that children know much more than we give them credit for and allowing them a space to talk about their thoughts is much more healthy than shutting down these conversations. She has also observed that the children who attended the funeral seem to be more comfortable talking about her son than the ones who did not.

"I'd rather sit with my nieces and nephews rather than my friends to talk about my son. I just wonder, do they think everyone's going to pass away?"

When discussing the honesty of children, another parent shared this story with us: **"We were in the car with my niece and nephew and my niece said 'I have 9 cousins. Some people might say I only have 8 cousins but I have 9 because... is my cousin and will always be my cousin'. It's so matter of fact for them, it's okay to talk about it, there's no walking on eggshells'.**

Talking to older children can be more difficult to navigate. A parent commented that they often talk most honestly when you are driving and you are not really in a position to have a deep and meaningful conversation. A parent told us about a comment made by her 10 year old daughter when discussing her birthday celebrations. **"She said she didn't want to have another birthday as it is one year closer to death"**. Her brother had died at the age of 13 after a fairly short and very debilitating illness. Like many children she chose a time to make this statement when there was little opportunity for further discussion and she is now planning her birthday as if she had never made this comment. Sometimes children and young people give us hints about what may be worrying them, and we have to be alert to opportunities to explore these worries when the child is open to this. This can be very difficult as children, especially older children may want to protect their parents and not bring up their own worries and distress.

One of the fathers in the group who has a teenage daughter said he is very worried as she is not talking about her little sister. **"My older daughter, 15 years old, she's not talking about her little sister, only studying and on social media. I am worried that this may hit**

her in later life". He also told us that one day, before her sister had died they discovered that she did not go to school. They found out that she was at the Royal Women's Hospital in the prayer room praying for her little sister. Another parent commented that 15 is already a difficult age and coping with grief on top of that must be very hard. She has also had to cope with transitioning to a new school where people may not know her well or have known her sister. One parent told us about how difficult she found it when she started a new job after her child had died – **"No one knew about me or about my child. It was very hard"**. Many adolescents will find someone to talk to who is not a parent – a teacher, a friend, another relative. They worry about upsetting their parent or think the parent has enough to cope with already without adding their grief to this burden. Adolescents need time to be alone and to process things in their own way, but it could be helpful to include them in rituals and conversations about their sibling if they are open to this.

Many parents worry about the impact of grief on children. One parent told us that his child who was about 2 when his baby brother died is, **"an old person in a young person's body. He will be happy then suddenly sad and say 'I miss my brother'. He is far more sensitive and emotionally intelligent for what he has been through. He is such an intelligent soul. His brother has always been part of his life and we're grateful he got to know his brother"**. As a result of the experience of the death of his brother this boy has been exposed to different cultures and different understandings of life and death. Children are impacted by the death of a sibling, but this impact does not have to be negative.

A number of parents in the group talked about rituals they have developed to honour their child and keep them present in the life of the family. One couple told us they light a

candle at sundown every night and hope that when their next child is old enough that child will be able to light or blow out the candle. One of the other parents in the group told us that they light a candle every Saturday at about the time their child passed away. The sibling is included in this ritual and will light the candle and blow it out on his way to bed. The family continue with this ritual wherever they are. They have a battery operated candle for when they go away and they take this and a photo wherever they go – **"when we go away we unpack her photo and the candle. It is part of a ritual and acknowledgement and it makes her part of our everyday life"**. As mentioned earlier, another parent always has balloons as part of the birthday celebrations of her children and a silver balloon of their brother is always included. The child whose birthday it is gets to release the silver balloon and send it to their brother.

Another family always take a day off and go go-carting on their son's birthday as this is what he did on his last birthday before he became ill. A parent told us that they also take the day off and do a special activity on her daughter's birthday. The activity is something the 2 children would have enjoyed doing together. This year they are going to go bowling.

Another parent told us that she and her daughter had gone to Build A Bear and had made an 'I love you' bear to remember her son. Now they press the paw every night and the bear says "I love you".

The issue of the child's bedroom was also discussed as part of this topic of remembering the child and keeping them present in the family. Many families keep their child's room in some way separate or special. One parent told us that her child's room is the sibling's play room but has the name of his brother on the door and is always referred to as that child's room. Another parent said nothing has been changed in her son's room since he

first went to hospital. It was acknowledged that it is not always possible to keep a room for the child and that this is difficult if you move away from the home the child had lived in. One couple who are now expecting their second child told us how they needed to prepare their first child's room for the arrival of the new baby. They told us how hard it had been to pack up the room and paint it and reconfigure it so it will be the room of both of their children. They plan to have both children's names on the door and to have the names of both children on the ceiling in glow-in-the dark stars. It is particularly difficult, as this is the room in which their child had very happy times but also in which he died. Finding ways to make this a shared room is important and another parent suggested that it is likely that their second child will feel the presence of his or her brother in the room.

Including siblings in rituals or in decisions about spaces in the house is generally helpful. One couple told us that their son had not been able to get to his bedroom upstairs after he came home from hospital for a while so they set up a room for him in the dining room. After he died their daughter said that this was now the memory room. Together they are arranging this room to house special things of their son's and to be a welcoming place to be in to remember him.

One parent has now moved house and is in a rental property while they are trying to find a suitable home to buy. She told us how difficult it was to make the decision to move house and how hard it had been to pack up and move her daughter's room. In the end they felt they had to make a decision that was right for their living son as he needed room outdoors. **"The day it sold, I sobbed my heart out"**. Their daughter has a room in the rental house and will have a room in their new

house - **"We'll never pack up her room. Wherever we go we'll always have her room. I'm sure some friends think it's strange. We wouldn't dream of packing her things up. It's not a shrine, her cousins play in there. It's just a room where we keep her pretty things and can go in there and think of her"**. We also heard of an understanding removalist who unpacked and set up the daughter's bed as soon as they started to unpack in the rental property.

Another parent told us a terrible story of when he was moving their things out of the place where they had been staying to their new place. He had left some bags to collect on a subsequent trip and when he asked the landlord where they were he took him to the basement and showed him he had thrown them in the rubbish dumper - **"all those precious toys and things were in the bin. I was so angry. I made him climb in the bin and get them out"**.

One of the parents in the group asked how it felt to be in a different space when you move house. She said she finds it very hard even when they get a new piece of furniture in their house as it changes the space and it is different to how the space was when their child was alive. It was acknowledged that this is always hard but sometimes it just has to be done. Having a space for the child is important for many people.

A few of the parents in the group told us that they have seen a medium. For these parents this has been a comforting experience and has been affirming of their ongoing relationship with their child. One parent told us of the difficulty for her of the very different grieving styles of herself and her husband. Their child died as a baby and was healthy and happy for the first 4 months of his life. Following his death her husband did not want to talk about him or have any photos of him in their house. Her family as well as her

in-laws also follow this custom and are not willing to discuss her baby nor to share photos of him. She has been able to negotiate and have 2 photos of her son on display in their house. She told us that her young nephew was interested in hearing about his cousin and looking at the photos she had they visited family after the baby's death but sadly when the child's father saw what was happening he disapproved and insisted that she stop showing his son the photos. People in the group were very sad for this mother and felt she had been brave to come to the group. After listening to people in the group she decided to make a memory book of her child that she will be able to share with their future children. It is very difficult when culture and grieving styles clash so dramatically.

It was clear as the group discussion progressed that most bereaved parents know intuitively how to talk to children about death and grief. Older children and young people may not be quite so straight forward as they have more understanding of death and of the impact on themselves and their parents. There are a number of books available to help to explain death to children and a few of them are referred to below. I have also included some websites which may be helpful for anyone wanting more information on how to talk to children and young people about death and grief or who want to understand more about how children of different ages may understand death.

Thank you for all the people who attend the group and share their wisdom and experiences. We hope the group provides a safe and accepting space for those who attend and that this newsletter gives those who are unable to attend a flavour of the discussion and insights of the group.

The following is a very small selection of books that I find helpful and a few websites parents may like to look up. We welcome suggestions/recommendations

from parents about what books, websites or articles you have found helpful.

- "*Beginnings and Endings with LIFETIMES in between*" by: Bryan Mellonie & Robert Ingpen — Puffin Books 1983 A book with 'sensitive discussions about death and beautiful celebration of living'.

- "*My Many Coloured Days*" by: Dr Seuss with paintings by Steve Johnson and Lou Fancher.—Red Fox Books 1996 A book that can help children describe and talk about their emotions - 'Some days are yellow. Some days are blue. On different days I'm different too. You'd be surprised how many ways I can change on different Coloured Days'.

- "*The Next Place*" by: Warren Hanson Waldman – House Press 1997. This book is, above all, a celebration of life. 'Hear the music. Feel the warmth and be carried away along life's everlasting flight'

- "*Water Bugs & Dragonflies*" Explaining Death to Young Children. By: Doris Stickney - The Pilgrim Press 2004. This book is a simple little booklet that explains death using the metaphor of water bugs transforming into dragonflies. There is a prayer and some biblical passages and suggestions for what parents can say, but this religious theme is not evident in the story and doesn't have to be used if this is something that feels right for your family.

Some websites you might find helpful are:

- The Australian for Grief and Bereavement grief.org.au This website has access to publications and resources including some information sheets about children and grief and an online bookshop.

- The Dougy Centre, The National Centre for Grieving Children and Families (US) dougy.org. This website has resources for grieving children and families.

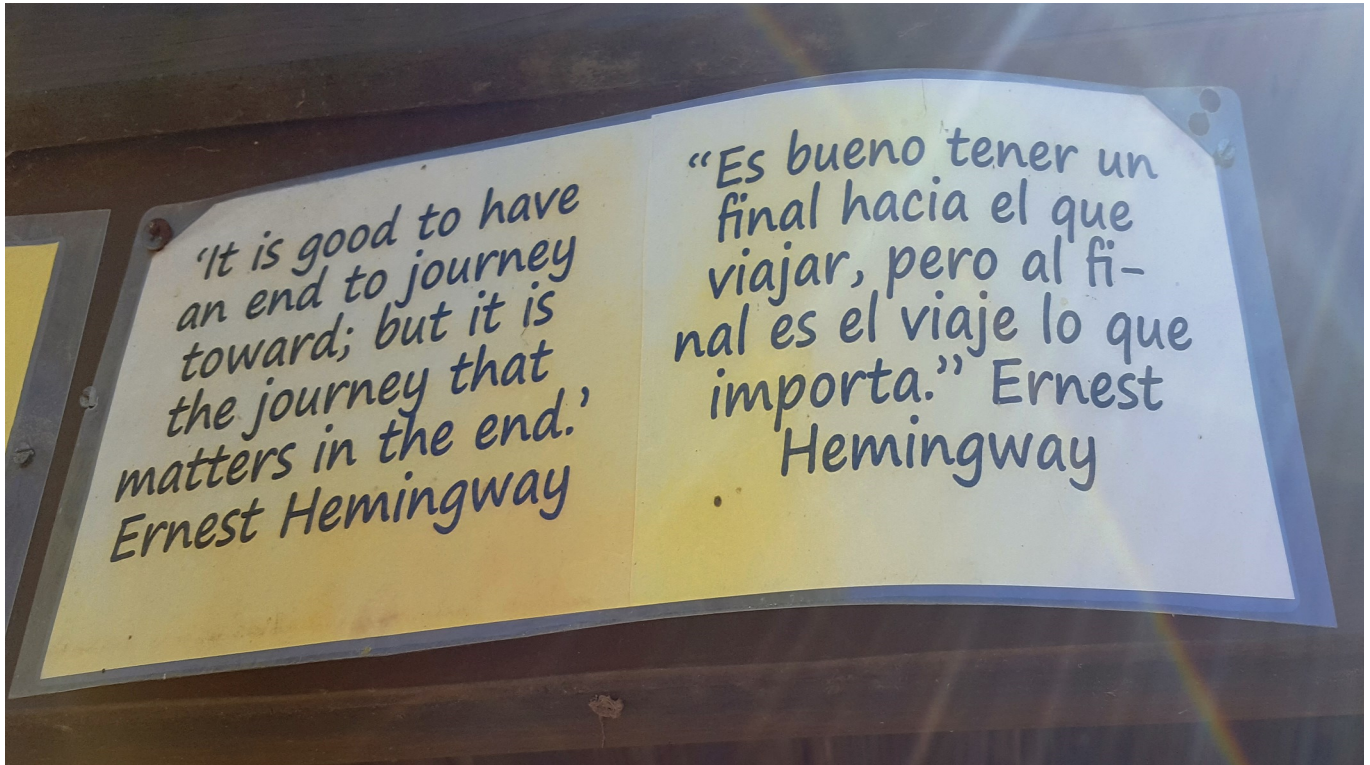
- Red Nose (SIDS and Kids) <https://rednosegriefandloss.com.au/>. This site has some articles and publications which may be helpful.

BackgroundLabs.com

Straight from the Heart



Thank you to Mary, mum of Cristian for her contribution.



The Royal Children's Hospital has an annual memorial service for families who have lost a child. This is held in August. As part of the ceremony we have a bereaved parent speaker, who shares some of the story of their child. We are looking for volunteers who would like to share their story. Here is a comment from bereaved parent, Claire, who has been a speaker at this service:

"I felt extremely privileged to have been asked to speak at the RCH Memorial Service back in 2014, as it gave me the opportunity to share Sian's story with other bereaved parents and their families (and who doesn't like to talk about their children!). Whilst the thought of speaking in front of a crowd can be quite overwhelming for some people, I can honestly say that once I started speaking about our precious and much loved Sian, my nerves just disappeared, and by the time I'd finished, I felt so empowered and proud. And I just knew that Sian was so very proud of me too! It's an experience that I will treasure and hold close to my heart forever." Claire Wilson – mum to Sian.

If you are interested or would like to know more information, please contact Paul Hammat: Paul.Hammat@rch.org.au Tel: 9345 4699

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:

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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
address.****

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

**Thursday 17th May
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:

“Grieving and Literature - what have you found that helps”

Many parents talk about books they have found that have helped in their grief.
We invite you to bring along and tell us about books that you have found helpful.

Please join us in May

The newsletter is always a team effort.

*Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter
and to Kate Shelton for scribing parents' statements.*

*Also to James Megalakakis 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

