FAMILY BEREAVEMENT SUPPORT PROGRAMME

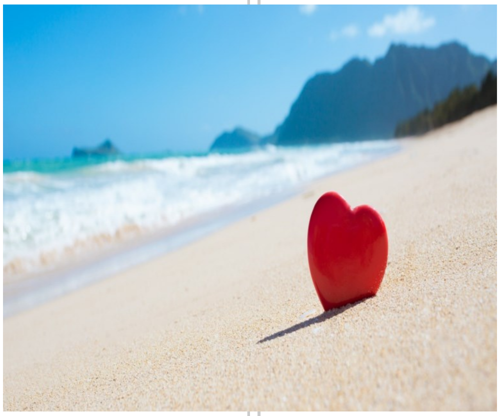
Social Work Department

NEWSLETTER JUNE 2023

The Royal
Children's
Hospital
Melbourne

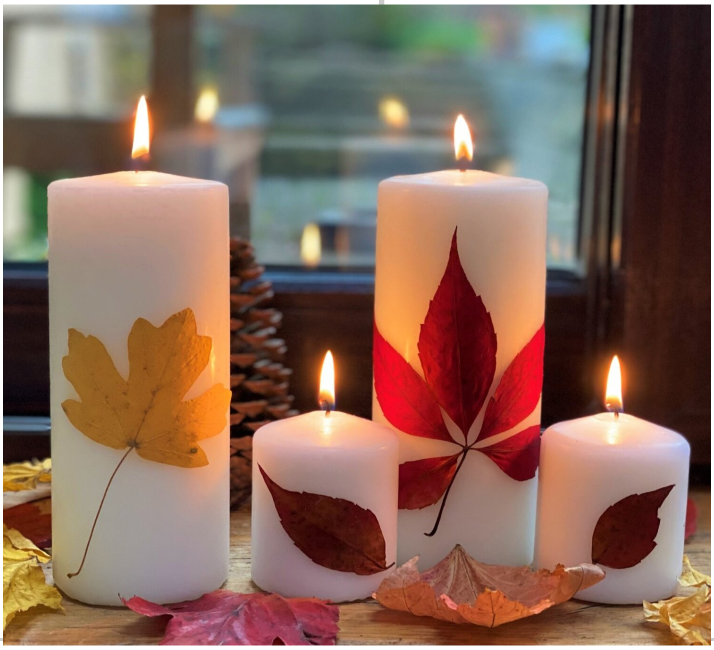
“Managing relationships with the other children in your life”

Welcome to the newsletter of the June bereavement group. June’s was a small group with 5 parents sharing their stories and discussing their experiences and thoughts about the other children in their lives. Parents began by introducing themselves and their children to the group. One couple told us that their daughter had lived until she was almost 19 years old. As she was their youngest child, her siblings are all young adults, 2 of whom still live at home. A grandchild had also recently arrived. The parent of another child told us that he is a twin. He had a lot of health challenges throughout his life with over 100 hospital admissions and over 40 surgeries. However, **“He was a happy child, a great character”.** His health had been improving, he was walking and loving life. He was thrilled when he was able to participate in the school sport’s day and managed to get around the school oval in an event. He was given a special award. He said **“I thought the worst was behind us, but then he contracted a virus. We still thought he would get over this like so many times before, but this time he didn’t”.** He described the heartbreak of seeing all the gains his son had made being gradually lost during his illness. Another parent told us that her child would now have been 17 years old had he lived. She said, **“It feels like a lifetime ago now”.** She now has an 8 year old son and has the experience of helping her child know his older brother whom he never actually met. The other parent in the group had a baby who lived for 9 weeks. He had a rare condition that was difficult to diagnose and understand at the time. When he was born, he had a 2 ½ -year-old brother and now has twin younger siblings. When talking about the grief of these losses, one parent shared with us a lovely analogy of grief – **“I feel grief is like being in the ocean, some days it feel like I am treading water in the calm seas but I am anticipating a huge wave of emo-**



tion and grief, but I know it will pass and the water will be calm again".

Some of the more recently bereaved parents spoke of their concern about how one of their other children is managing the loss of their sibling. One parent told us that she feels that one of her living daughters is suppressing her emotions and avoiding her grief. **"She pushes us away and becomes defensive or combative. She either arks up or shuts down. Otherwise, she acts as if everything is normal".** They told us that she avoids the part of the house that was set up for her sister and avoids talking about her. She never goes into her bedroom or looks at photos of her. She is keeping herself very busy with 2 jobs, her boyfriend and anything that keeps her out of the house. She has just left for a trip overseas. Another parent also told us that his daughter: **"is doing well, which I find difficult. She acts almost as if he never existed, it is just business as usual".** He told us she spoke at her twin brother's funeral and only appeared to get upset when the hearse drove off with the coffin. Both of these parents found their child's behaviour difficult to understand and were concerned that their child was not processing their grief in a healthy way. They worried that this may have implications for them later in life. Another parent in the group was reassuring and said that people process grief in their own ways and that maybe there is an element of these children also protecting their parents. Life has changed significantly for these siblings – everything is different and even for a young adult this may be profound and disorienting.

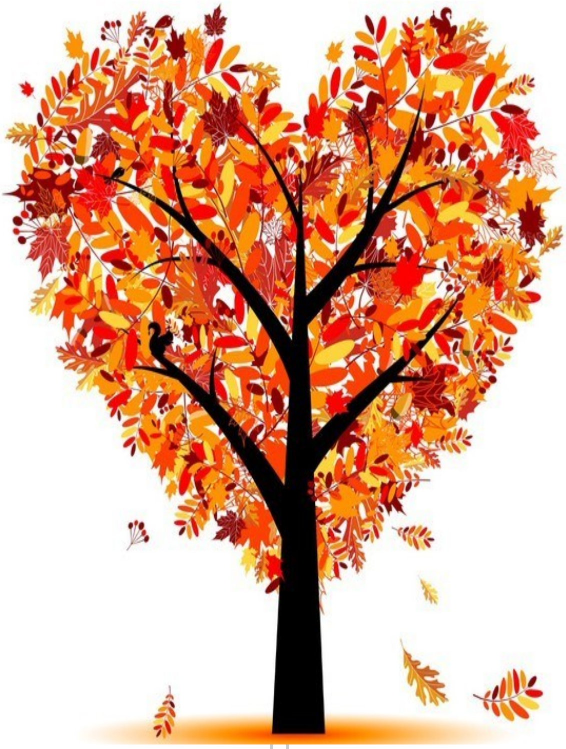


One parent said: **"As parents, you teach your kids how to read, ride their bike, tie their shoelaces. I don't know how to teach them how to grieve".**

Parent told us about how her son who was 2 ½ -year-old when his baby brother die. The 9 weeks of his brother's life were very intense and traumatic. The mother told us of the very close connection between the 2 boys. She said that her baby, who had a rare seizure disorder, would cease seizing when his brother was in the room and would feed from a bottle only when his brother was with him. She believes this very close connection has resulted in her son being deeply affected by his brother's death. She told us about his anxiety that something may happen to his younger siblings and his need to be close to her or to know where she is at all times. He is seeing a psychologist and she feels this is helping him and helping her to understand what he needs. She also told us that she feels her son has different memories of his brother than she has and she just wants to absorb all these memories. She said – **"I want to hear everything they say, because I never heard him".** She told us she is very protective of her son – more so than of his twin siblings, and she struggles with being separated from him for long periods – **"The 6 hours he is at school is about as long as I can cope with".**

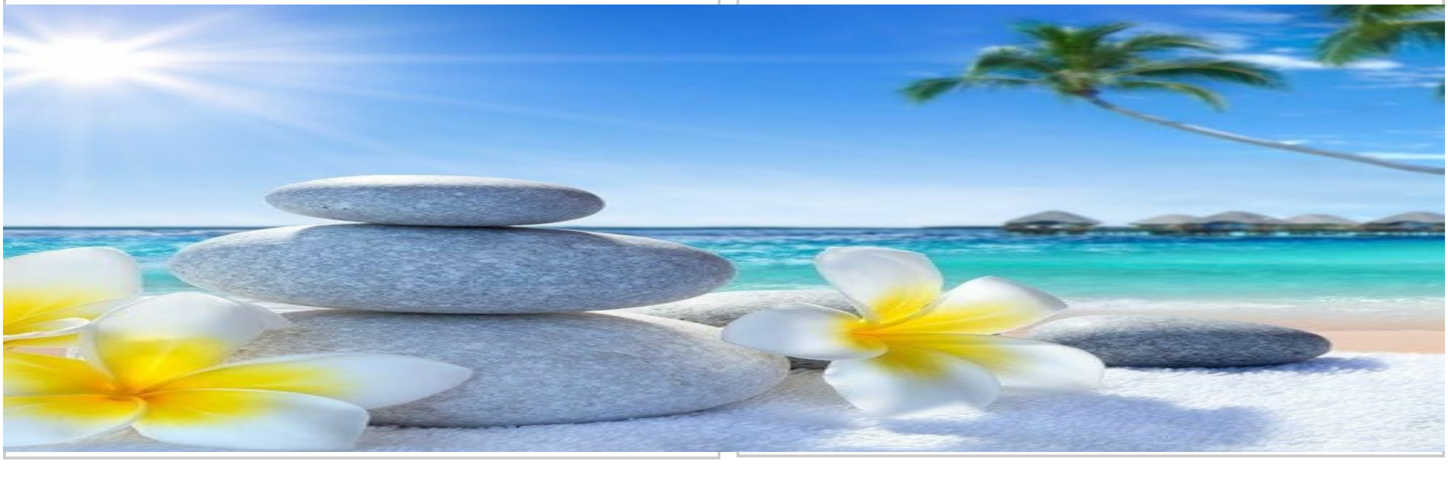
Children born after their sibling's death will have a different experience of sibling loss. Parents who had subsequent children spoke of how they acknowledged the older sibling to the new child. Two parents in the group had given their younger child the name of the older sibling as a middle name. One parent told us that her second child, when he was quite young, refused to acknowledge his middle name and insisted he only had a first name. Now, at the age of 8 he is proud of his middle name and speaks openly about his older brother. A parent has twins born subsequent to their brother's death and commented on the close connection between one of the twins and her deceased brother. She has her brother's name as her middle name and is very connected to the teddy bear that contains her brother's ashes. She described her as having **"Two souls in one body".** This little girl recently used a pet name for her brother when asking for the bear. Only his mother ever called him that name and the mother said she had never used that name in the presence of her daughter. She said **"I love how connected they all are, it makes it worth getting up in the morning to witness".**

Other parents also spoke of the importance of their other children in getting them through the day, particularly in the early times. One parent described her child as **"my lifeline and my best friend. I am obsessed with him".** She told us that without him she probably would not have got out of bed after her child died. She also told us that she is confident that her marriage would not have survived the death of her baby if not for their other child. Another said **"If I didn't have another child to pour myself into, I don't know what I would have done or where I'd be".** A parent told us how he has lost his routine and purpose – **"My wife went back to work some years ago and I took on the fulltime care of our son….He was my life, my days feel empty now".** He told us caring for his daughter gives him some structure for his days although it also brings many reminders of what has changed – picking up one, not two children from school for example.



The parents in the group who had children who lived with disability told us that they had always worked hard to make sure the siblings did not miss out. One parent told us, "**We made the decision early on that I (mother) would provide all the care and the siblings could just be siblings".** Now the situation is very different, as it always is when a child dies. One mother told us, after being the primary carer for her daughter for almost 19 years **"I can now put myself first".** While this is a completely new experience for her, she is becoming more comfortable with it. Another parent commented on how easy it is to live a more active life now. They can leave the house with more ease, go to the beach more often and spend more time in the surf. There is some feeling of guilt associated with all of this. Parents in the group also talked about feeling guilty when they were having a good time and momentarily forgot their child had died. One parent said: **"What right do I have to be happy"?** Another parent reflected on this comment and said: "**We are looking for triggers to be sad……we choose to play a song or music that evoke an emotional response".** He asked the other parents in the group if they deliberately hide their emotions from their other children. There was a mixed response to this in the group with some parents feeling it is very important to let your other children see you grieving and others feeling they wanted to protect their other children from their grief. A father told us about a pond in a park they frequently walk past – his son always wanted to stop and count the fish. Now when he walks past it with his daughter, he gets teary but tries to hide this from her. One parent felt very strongly that you should not hide your emotions from your children. She told us: **"It is important for children to see that parents can express strong emotions and still be okay. It is important for them to see us distressed".** Most parents felt that their children were more comfortable with emotions than many of their peers and could talk openly about having a sibling who had died. The difficult question of 'How many children do you have' was discussed, with parents generally feeling the answer to this question depended on who was asking. One of the parents said that her other child would be unhappy with her if she ever did not acknowledge his sibling.

Parents had many ways of remembering their child. Many had lots of photos on their walls. A mother told us that her other son asked why there weren't as many photos of him. She told him she sees him every day and doesn't need to have photos up to remember what he looks like. Another couple have a frame containing their daughter's photo and casts of her hands and feet as well as one of her curls. This is up on the wall in their lounge room although one of their daughters said she thinks this is 'morbid' and avoids looking at it. The full moon is significant for another parent **"He loved the full moon. I am always looking for the full moon now".** He also reads the story book with his daughter that his son insisted on having every night and which they all know by heart. Celebrating significant dates, particularly birthdays was something most parents do but can cause challenges. A long time bereaved parent told us that in the early years she had celebrated her son's birthday each year and invited her family. Some of the family did not understand why she would do this, saying **"You're meant to have a birthday for someone who is living, not dead".** Now they still celebrate the birthday but more intimately, with just the immediate family. She has learned that you pick and choose who you confide in and who you trust with your grief. She has seen a grief counsellor and psychologist and is now more comfortable with people's reactions. She said: **"I still struggle with empty and judgemental comments, but you can't control other people. People who want to remember will remember and acknowledge him….I have no expectations and therefore no disappointments in others, especially people I thought would care more".** Celebrating the birthday of a surviving twin has particular challenges. She had thought her brother would still be there to jointly celebrate their 10th birthdays. Their father said he wants birthdays to be a celebration for his daughter but there also needs to be some



space to remember his son – a difficult balance. A parent told us that her son's ashes are in a teddy bear that sits on her bed. The other children can play with it and it comes with them everywhere – still a part of the family. She told us she organised a big birthday/ fundraiser event for her son's first birthday - **"In the early days I drank 1-2 bottles of wine a night but then I threw myself into organising a 1st birthday party/fundraiser. I didn't really allow myself time to grieve until after that event".** As with the adult sibling discussed earlier, being busy was a mechanism to ward off the pain of grief. She told us she didn't really allow herself to grieve until this party was over and she couldn't avoid the grief anymore.

A parent whose child had an undiagnosed but degenerative condition shared with us some difficult thoughts: **"This could sound awful for someone who has not experienced this, but I feel it was his gift to us that he died. I don't think I could have done all the things he would have needed had he continued to live".** Another parent whose child would have required a very high level of care had he lived agreed. The parents whose children had lived with disability and required many of these interventions many times daily told us that it becomes second nature, and you cope with these things as a normal part of your care and love for your child. This discussion shows how different we all are, and we do not really know how we would cope with different circumstances. This does not reflect less love for the child or less grief for their loss.

Over the years this group has been running we have heard many stories of children and young people coping with their sibling's death in different ways – many of which have worried their parents. It would seem that we must allow children and young people time and space to work this out for themselves, to talk about their grief or to not talk about it, to find someone else to share their feelings with and not always expect they will talk with their parents, and to grieve in their own ways – just because we do not see them grieving does not mean they are not. Providing a space where they know you are open to listening and to talking about their sibling and are willing to be led by them will allow them to express their grief when, if and how they need to. Children and young people may use other means to express their feelings – play, art, music and other creative media. Be patient and trust in the process. They will be led by you so it is important that you also give yourselves permission to experience and process your own grief.

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Resources (grief.org.au) This website has some resources about how children of different ages experience grief and how you may be able to support them.

Ages and Stages | Guiding Light - Red Nose Grief and Loss This is a general fact sheet about how children of different ages may experience grief and how you can help them.

We thank all the parents
who participated in this group
and shared some often
difficult and very personal
reflections.
I have included some links
to some information sheets
about
children's grief
which may be helpful.

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 will be held on:

Thursday 20th July 2023
7.30pm—9.00pm
The RCH Foundation Resource Centre
Level 2, 48 Flemington Road
Parkville, VIC 3052

Please join us to discuss the topic:

Making space for life amidst grief – giving permission for contradictory feelings.

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

The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating the group discussion and writing the newsletter,
Thank You to Sally Clarke for scribing parents' statements.
And thank you Marina Puljic for ensuring the
newsletter is formatted, collated and distributed to interested people

Social Work Department, RCH