

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER APRIL 2023



## *“Grief and Hope”*

We had a number of new or recently bereaved people at our group this month. Three of the four families in the group had been bereaved for less than 1 year. One parent commented that **“all the days are rolling into one”**.

The topic of grief and hope was a challenging one, as many parents find it very difficult to think about hope after their child has died. Coincidentally, a parent emailed to tell us the story of her daughter and her sibling. In her email she told us that her baby daughter died over 14 years ago. One of her sons was 6 years old at the time and decided that he wanted to be a nurse and to work in the RCH NICU. He was greatly influenced at the time by 3 particular nurses who were caring for his baby sister. Now, 14 years later he is an undergraduate nurse working in the ‘Registered Undergraduate Student of Nursing’ program in NICU and Koala at RCH. He hopes to do his grad year at RCH also. She wrote: **“I am so proud of the man that 6yo boy has become. I am proud to hear him come home with the stories about his day.....I hope he will have the same positive influence on others that those three nurses had on him.....I wanted**

**to share this because it shows how such sad circumstances can have such a positive outcome”**. She also said: **“I know it can be hard to see anything positive at the time and for a long time after, but we have had so many positive experiences as a result and I wish I had known that at the time. It would not have made it any easier, but ....., it would have given me hope”**.

One parent commented that life sometimes feels like the movie, Sliding Doors. The movie explores 2 different realities for the same person. He said he can: **“Look back and reflect on things that might not have happened if their son had not passed away”**. This parent could acknowledge that some things they do now they would not have done if their child had not died, but this does not mean that he would not give anything for his son to still be with them.

Another parent told us that she has formed a very close friendship with another parent of a child who died in similar circumstances. She also told us that in the beginning she did not want to be far from her child and she could not make any long-term plans. Now, 4 years on it is beginning to get easier and she is able to think and make plans into the future.

A more recently bereaved parent told us she feels **“nothing good can come of this. It is not what we wanted. I think of her all the time, at every event”**. She feels her child’s absence everywhere and cannot imagine that there can be any hope for good things to happen. A parent spoke of things being bitter-sweet. **“You can find joy in new events, but also wish they were here”**. There was some discussion about holding 2 conflicting emotions at the same time. Parents commented that they never thought this was possible, but now know you can feel joy at a particular event while also feeling deep sadness and grief at the same time.

Parents in the group talked about how hard it is to know what to say to people when they ask about your child. A mother said: **“You find yourself comforting others when you tell them. It should be the other way around”**. A father shared his experience of a local café owner who had not heard about his daughter asking him about her. When he told him she had died the café owner just gave him a big hug. He reflected on how strange this situation feels. He also told us he



doesn’t tell people how he’s going now nor ask them how they are going, but just says **“g’day”**. Other parents commented that they feel people don’t know whether to bring up their child or not. When the question about your child or about how you are is asked, some parents chose to have honest conversations about how they are feeling when they believe the question is genuine and not just social convention. One parent said: **“If people are close to you, they will ask how you**

**are. If you push people away, you have nothing. Communication is key. You need to let your emotions out, otherwise you’re a time bomb”**. There was quite a lot of discussion about how it felt to be asked ‘How are you’, even when it is genuine. Parents felt that sometimes they just wanted to be left alone, but at other times they really wanted to be asked and for their grief to be acknowledged. Whether they wanted to be asked largely depended on the situation, who the person was and how they were feeling at the time. While at times they just wanted to be left alone, they generally felt it is better to be asked and their grief acknowledged, than not.

When talking about how it feels to be a bereaved parent and questioning whether it ever gets better, a parent said you never stop grieving, although it changes over time. A more recently bereaved parent asked if time makes you feel like you are letting go or forgetting your child and the little details. A parent responded that you never forget: **“You find ways of incorporating them into your life. There is less raw emotion and you break down less”**. There was also discussion about what details you may forget over the years. Parents said there are some events where the details never fade, usually the more traumatic ones, but over time some of the little day to day details of the child’s life do fade. One parent pointed out that we cannot remember every detail of the lives of our living children, so it is perhaps unrealistic to expect to remember every detail of the lives of our deceased child – **“but with the child who passed away you want to hold on to all the details”**. The big difference is that there are no new memories of the child who has died, while there are always new memories of living children. A father said he feels he is forgetting details and that bugs him. Many parents make photo books of their child as it helped to remember the details. Making a book can be hard and completing it even harder. One par-

ent talked about how emotional it was preparing photos for their baby's funeral. Parents talked about how looking at photos or videos often prompted memories. Some parents 'rationed' their photos so they had new photos to look at later. Some friends send photos of the child when they come across them. One mother told us how, when it is a photo she hasn't seen before it is almost like finding a new memory.

Seeing other children either who were peers of the child or who are the same age can be a trigger for grief but can also bring comfort as memories are triggered. A parent had her daughter's best friend over to play and told us that this was a very bittersweet experience. She said: **"I hadn't thought about the impact on me. It was very triggering.... bittersweet. She is a 'marker', a reminder of what she would have been doing"**.

The conversation moved to the impact on other members of the household. A parent spoke of watching her younger child grieve the loss of his sister while another parent spoke of the pain of watching her daughter's little cousin (who lives in the same household) grieve and not really understand why his baby cousin isn't here anymore. His mother said his behaviour has changed and he is tantruming a lot more, but the attitude towards him of others in the household has also changed due to their own grief. He is much more likely to be given whatever he wants and not to have many limits placed on him. Routines have changed as before the routines included the baby and now she is not there. It can be very difficult to

know how to respond to the sadness and confusion of young children and to know how to explain to them what has happened. A parent said: **"Everyone feels the void"**. One parent told us that their older children find it hard to know what to do. They are grieving the loss of their sister but are also mindful of their parents' grief and don't want to say or do things to upset them. They are reluctant to talk about their sister for this reason. In another family the grandmother who is part of the household, was minding the baby when she stopped breathing. Her daughters talked about how she is struggling with her grief and with the fact that she was minding the baby at the time. They both reassure their mother that they are glad she was there as they felt she was more able to manage the situation than they would have been, and her actions enabled them to have a few more precious days with their baby. Other parents commented on the changes in the behaviour of their child's pet and how this is also upsetting, seeing even the animals in the house grieving. One family's dog died shortly after their daughter and the father said – **"I think the dog had to go take care of her"**.

Returning to the theme of hope and grief parents began to talk about how they felt when they did have a moment of feeling happy or of not thinking about the child for a little while. One parent said she felt guilty when she realised she had not thought about the child for an hour. A father said: **"I have intense feelings of guilt if I laugh, or forget anything. I think to myself 'you're selfish'. You have to be able to be happy and**



**sad but this is hard and takes practice**". He has found that he has to allow himself dedicated time to feel and express his emotions. He needs to release his emotions regularly or they build up and come out in intense and inappropriate ways or times.

People in the group shared ways they try to manage their grief so they can get through each day and the things they have found are not helpful. One parent said she is surprised by how physical grief is. **"You can feel it in your body. You feel different. You know the emotion is coming"**. She also said she finds adrenalin does not help with her grief. When you get too much adrenaline you just crash. It is best for her to try to keep things calm and on an even keel. Another

parent tried to avoid the pain of the absence of his daughter by working frantically to organise a team for Run for the Kids. He spent many hours organising this and participating on the day with a team of almost 100 people. Part of him knew this was not good for him and he crashed badly afterwards, taking days to recover.

One father in the group told us how he felt very pressured to be **'strong'** at home in a household where he is the only male. **"As the only man in the house I feel I am expected to be the strong one and cannot be emotional"**. Another father told us how he wakes up every morning and cries as the reality of another day without his child hits. He builds in time each day to sit with his grief and let his emotions out. He also told us he tried to return to work but realised that in that world nothing had changed while in his world everything had. He decided he just could not manage to be back at work.

Friends can help but they can also disappoint One parent said: **"I can see the good in**

**some people, see the depth of people"**. You can also be very let down by people you thought were friends. Some of the parents felt a lot of anger towards people they thought were friends but could not handle the situation. One parent told us about some people they had really gone to a lot of effort to help out at one time and who they considered good friends and how disappointed they are that these people have never even spoken to them about the death of their daughter. A couple whose child's death was expected due to a tumour said they felt their situation was different to others in the group who had no warning that their child was going to die – **"Our situation was very different. We knew he was going to pass and our friends**



**we were also aware. It was not a shock like it was for others in the group"**. A father commented on how helpful it is to come to the group and to be with people who are also grieving the loss of a child. He said: **"the group is helpful. I can't talk like this with anyone else. It is knowing other people go through what you are also going through"**. Other parents agreed about the importance of knowing other people feel what you do. He said he was not proud of some of the things he felt – for example, feeling glad that other people were experiencing what he was after certain disasters. Another parent said he felt angry at people grieving the death of older people who had lived a long life. These things can be said in this group but perhaps not elsewhere.

When we began to talk about how you can possibly adjust to a world without your child a parent commented: **"You can get yourself in a bad place if you try to understand why this happened. You need to focus on how you will get through"**. Others in the group

spoke of how hard it is to accept what has happened – **“I hate the term acceptance. I will never accept that it is okay”**. One mother told us how she didn’t cry, even when she knew her child would not survive – **“I think I was always expecting a miracle. It still hasn’t kicked in – I am still expecting a miracle... I go through the bible and see miracles happen to other people, why not here”?** Another parent agreed that it has taken months to accept the reality of what happened. Now it seems more real but this makes the grief worse. Some parents have had the experience of dreaming about their child. The dreams make them feel close to the child. One parent advised that you should write down the dream so you can remember and go over the dream again, almost like new memories. One couple told us that they both dreamed of their child on the same night. A father told us, **“sitting quietly and thinking about her is the closest I can get to her”**.

We finished the group by reading a beautifully illustrated book by Shaun Tan – The Red Tree. This book describes in words and pictures the experience of grief and, at the end of the book, the presence of hope. A video of this book can be found on YouTube: The Red Tree - YouTube Parents in the group agreed that the writer had captured their feelings accurately, sensitively and powerfully.





*I would like to thank the people who attended the group  
and shared their stories, feelings, experiences and wisdom  
with each other.*

*and with the wider readership of this newsletter.*

*I would also like to thank the mother who shared the story of the  
impact on her son of her daughter's death 14 years ago.*

*I hope all of you reading this newsletter  
find something that resonates with you.*

*If you have a story you would like to share with us, a book review or a  
poem, please send it in and we will publish it in the next 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](mailto:Bereavement.Services@rch.org.au)

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

**Thursday 18th May 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:

**“Expressing grief: different ways, different times, different people”**

**If you wish to attend this group please**  
**email: [Bereavement.Services@rch.org.au](mailto: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 Sarah Martin 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**



