FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER SEPTEMBER 2024

The September group was the first daytime group we have run. It was a small group, but the participants were able to share their stories in more depth than a larger group could allow. We did not focus on the topic we had anticipated but talked more about the individual stories of the group members.

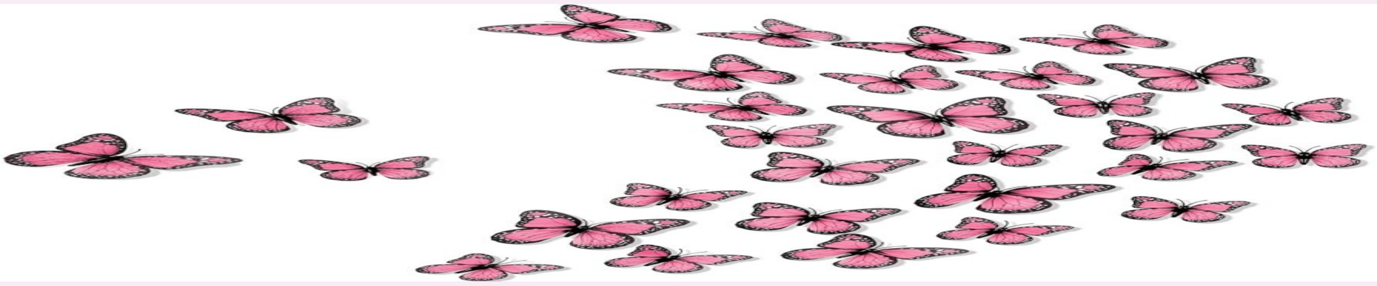
The group met in the pastoral care space near the Family Hub. One parent told us how he and his wife used to come to this space and would use the white pebbles in the garden to write their child's name in the pond there. To access this space parents had to walk into a busy day time hospital and past a busy café. One parent had found this unexpectedly difficult, even though she had visited the hospital several times since her son had died. She told us: **"Walking through the hospital in the daytime is a very different and confronting experience. I thought I would be okay, but I suddenly got very upset and panicky, it came out of nowhere. Where did it come from"?** For her, this rush of distress felt like a tidal wave. For this parent there were no negative thoughts or feelings about the hospital – **"RCH is like a second home. He spent his whole life in hospital. I love the smell, everything".** Another parent responded that he believes that grief can be a very cellular response. He said it can just hit you unexpectedly and your body seems to respond, without conscious thought. A parent commented that when she sees other families with sick children like hers, she feels for what they are going through and where things may end up – **"It hurts my heart that others have to go through this too".**

The parents spoke of the things that trigger them. For one it was seeing other babies that remind her of her own child but for another parent it was the sounds of the machines – the pings and beeps. Other parents have spoken of the sound of an ambulance being a trigger for them.

We had a discussion about how the parents remember and think of their child. One parent told us his baby, born healthy but being rushed to the RCH at 4 days of age changed from a tiny, prem baby to a baby bloated with fluids. He had 8 tubes in his tiny body and machines attached to keep him alive. The baby's size and appearance changed depending on how well his fluid balance could be managed. This father found the sounds of the PICU traumatic more than the buildings or the space. They did not have a lot of photos of their baby from the birth hospital, but they did take photos of him at RCH with all his tubes. **"Good friends photoshopped and removed the tubes. We have beautiful photos".** Due to the environment in PICU, this baby had goggles to protect his eyes – his 'superhero goggles'. This parent said: **"I don't have a lot of memories of him in the bed – it is his soul I remember. I have a different relationship with his soul and his body. I don't hold onto memories of his body, I don't focus on that side. I focus on the wattle outside. I can't focus on the trauma his body went through; it is too distressing. I don't want my memories to be that".**

In contrast another parent told us how she had many photos of her son throughout his life and remembers how he looked every day of his life. She spoke of her pregnancy; **"I loved being pregnant. I really wanted to keep him with me. Once he was out it was going to be out of my control".** This mother knew her baby had a congenital heart condition that meant he would need to go the RCH as soon as he was born and have several open-heart surgeries. She shared with us her anxieties that emerged during her pregnancy and of how she developed a fear of sink holes – "I didn't sleep, I had a real feeling that a sinkhole was going to swallow the whole house". Another parent commented that for him "**Sinkholes opened up, the world opened up and we were in free-fall. We'd cry ourselves to sleep then get up and do it all again".** The mother said that the fact that no one outside of the medical team would talk about her baby being sick made her anxiety worse. She also told us that she felt her medical team tried to convince her to terminate her pregnancy. **"They said; "are you sure you want to have him?", I said "you have to stop asking me – I won't change my mind, I'm having him".** It is hard knowing you are carrying a sick baby, and the birth can be scarier because of this. This mother delivered her baby by caesarean section. She was only able to hold him very briefly after the birth before he was taken away – **"They brought him up before NETS took him to RCH – he looked peaceful. He had a beanie on that I still have".** Grief was compounded by the fact that it was her family or nurses that did many of the 'firsts' such as reading him his first story and changing his first nappy. **"I got day leave to see him the day before his surgery, he was so aware and looking around, but I felt like he belonged to the nurses. I felt like he was mine when I was pregnant….I felt like he didn't know me".** She spoke about how hard it was trying to care for herself post birth and trying to be on the ward as much as possible – **"It was a lot. It felt like crashing waves constantly. Not every day, every hour! I didn't know all the terminology. I thought new baby smell was the hand sanitizer smell".** The feeling of being an onlooker as your child is being treated in a highly medicalised and technological environment is a common feeling for parents. This feeling of being out of control was compounded for this mother by a change in the diagnosis of her child's heart condition after he was born – **"I had researched the condition I had been told he had, but I did not know about this new condition".**

The parents in the group spoke of the personalities of their children and the trauma both baby and parents experienced throughout the child's time in hospital. One parent said – **"He was gracious. Everything**



they did he was okay with; he was telling me 'I'm okay mum'. You can't ask them if they are okay. I know when I am in pain, I want to tell someone". Another parent said: **"You have a responsibility to protect, but I couldn't fix it. I have a lot of guilt. I had to forgive myself – he wasn't being punished for something I did".** Seeing your child going through surgeries, interventions and procedures is traumatic. A parent spoke of holding her baby when a MET was called. She stayed with him as he was intubated even though the nurses recommended she leave the room. She said: **"I needed to be there for him, no matter how traumatic it was. No one knows what a good mother I was and how hard it was".** She reflected on the experience of practically living in the hospital for most of her child's life and how even her husband didn't know what this was like. He found it extremely difficult being in the hospital day and night during their baby's last days – he wasn't used to the machines and the activity of the hospital at night. Another father told us that he and his wife spent 18 hours a day on the ward and 4 hours back at Ronald MacDonald House. Family and friends brought the sibling in at times and they would spend time with him in the park.

When this mother was asked how she remembers her child she said; **"I always think of a beaming child; but then I think, he is not here; and then I think of why he is not here".** The parents spoke of the impression they believe they give others and of how difficult it is to convey the true complexity of their feelings and their grief and how this plays out in their lives and relationships. If you are happy, do people think you are not grieving anymore? If you are sad, do people want to keep away from you? If you say something profound or wise, do people think you have found the right way to live with your grief? **"Sometimes I think I didn't talk about how cute he is, I worry that people will think I don't miss being with him".** One parent commented that he felt the other parent had changed since he first met her, that her face has more light. She acknowledged that she is in a better place than she was when she first started to attend the group; **"I get afraid that I am the darkness, that people won't want to be around me…….I worry I don't have any joy, everything seems mundane. I can giggle in moments but I am a different person. I am not a happy person. I try to be happy".** Another parent told us of a time he and his wife had dinner together in their child's hospital room – **"The doctor came in and said 'It's good to see you laughing' because he had only seen me sad".**

The difference between how people manage grief and trauma has been an issue for one couple. The mother said she thought her husband was in denial when they learned that their child was not going to live much longer. She was angry with him at first when he kept going to work – **"I was thrown when he chose to go to work after our child was palliative….I was like, how did you think work was more important"?** She also recognised that she had much more opportunity to talk about what was happening with their child – palliative care met with her, she was at the hospital all day, she saw the changes in her son every day and throughout every day. She has come to understand how her husband manages his grief – **"He doesn't like to confront things head on. We are two different people…………He would run away when bad things would happen would happen".** It took some years for her to understand this. She said it is important to understand but not to judge.

A parent said that he has learned **"You can't change the events but you can change the story around the event. The story about his death I can control. It is a guiding principle for me, I can control the direction in the journey".**

Towards the end of the group the participants acknowledged that even within the group, each story is different, and each person’s grief is different. Hearing and telling the stories, each person finds something different that resonates. Everyone navigates grief differently and it is incredibly difficult to explain to others the complexity and many layers of your individual grief story.

Thank you to the parents who attended this group and generously shared their stories and listened to these stories with compassion. We acknowledge that attending the hospital in the daytime is very different to coming into this space in the evening and can be daunting for grieving parents. We will continue to work on finding a venue that may be less challenging to access. Please let me know if you would like someone to meet you somewhere and walk with you through the hospital. You can enter the hospital from the green lifts and walk past the café to the space. You can also enter from the area outside the family hub.

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

The next meeting of the

Family Bereavement Support Group will be held on:

Thursday 17th October 2024

10.30am-12.00pm

Murrup Biik, Pastoral and Spiritual care space. (please see map on next page)

Please join us to discuss the topic:

Fostering connections and drawing on support

This new iteration of the Bereavement group in a daytime format will consider the ways that group members find connection and support in their lives as they navigate their grief.

It will also explore what participants would like to focus on and draw from in this group.

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 and Jennifer Burn for facilitating the group discussion and writing the newsletter,

Thank you to Jennifer Burn 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

The Royal Children's Hospital Melbourne