

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER SEPTEMBER 2023



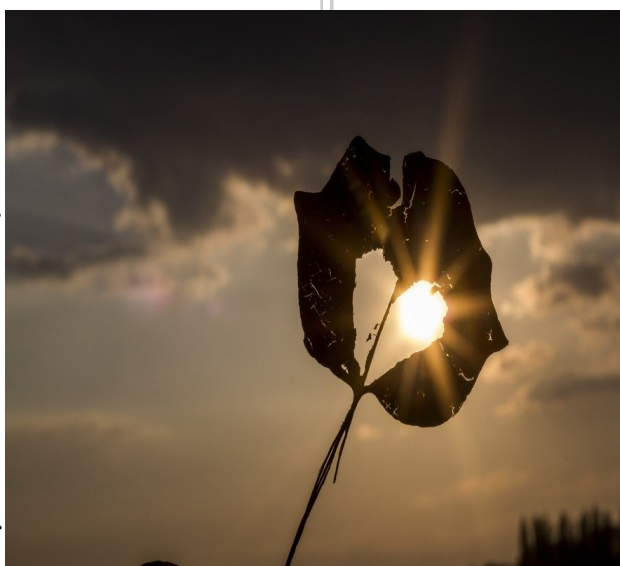
The Royal
Children's
Hospital
Melbourne

“ Identifying our strengths and how to utilize them in living with grief ”

We had 10 parents attend the September Family Bereavement Group. In the group we talked about strengths – the strengths people have, the strengths they learned from their children and the strengths of their children. We explored how these strengths help them along their grief journey. For some people this is still quite a new journey and others had been on this journey for some years.

A father in the group said his strength was gratitude. He told us: **“Gratitude has helped me get through grief and into joy. Instead of feeling pain and sorrow I am grateful that our son chose me and my wife as his parents”**. He told us that it took him time and an understanding of a different way of view-

ing life and death, to come to this feeling of gratitude. He described the feeling of great sadness after his son died as feeling like being in a ‘grief or dark house’ where every-



thing is dark and no light can get in. **“I couldn’t change the event but I could change the story. Gratefulness showed us light, and took me out of the grief room and let the light in. Gratefulness helped me leave the dark room and see that life is beautiful. Now I can live in the beauty”**. This process was gradual and had its ups and downs and now he spends less time in there and more time in the real world.

Sometimes, however he finds himself back in the grief room and at times it feels like a safe space. He also reminded us that even in the same family everyone’s grief journey is different. **“There are different timelines for leaving the grief house”**. This father told us that he believes his son came into his life to make him a better person, and now he is committed to make life

better for others – **“I want to make others’ lives better and richer for having met me. This way I can honour his soul for choosing our family”**.

The theme of making life better for others was echoed by others in the group. One parent raised money to buy a cuddle cot for the hospital to allow families to spend more time with their baby either at home or in the hospital by keeping the body cool – something she wished she had access to when her child died. Other parents have raised money for various charities or causes. One parent spoke of how he makes sure he speaks to other people with disabilities and/or their carers. He said, **“If it makes them happy, it makes me happy”**. There were other examples throughout the group of this generosity and desire to make life better for others.

As we continued to discuss strengths a parent told us that her strength is cooking and patience. She told us that as she was growing up, cooking for the family was a way her mother showed them love and now, it is something that makes her feel like a mum. She continues to cook a cake for her son for all his birthdays. She also told us that she learned patience from her son. **“Patience from my son and his experience as well as patience for my own grief. I gave myself patience”**.



A mother told us that her strength is creativity. She said, after her daughter died she had a lot of trouble sleeping so she decided to challenge herself and do something with all the energy she had following her baby not being around. She bought a sewing machine and taught herself to sew. She has now launched her own business and sells garments she designs and makes. She has

named the business after her daughter and in this way she keeps her baby girl alive. The baby's aunt is also creative, but she told us she doesn't have the patience to sew and design garments. She creates decorations for parties. She did all the decorations for her niece's first birthday party.

A couple of parents named organisation as their strength. They talked about how they needed to be organised to be able to care for their child, get to all the appointments and keep on top of all the medications, feeds and other cares their child needed on a daily basis, as well as running a household and caring for their other children. One parent said she misses the need to have lists and structure in her life and feels she now has organised chaos. In the same vein, another parent said: **“I miss being good at getting everything done and in place. I like the challenge and it takes my mind away from being alone. I like to feel needed and like to be busy. I was at my best when I didn't have the time”**. Finding ways to fill the days after a child has died is a theme we hear often in the group. Life feels very empty.

Courage is another strength a parent spoke about. Courage is a strength learned from a child who was always courageous and never complained through all her health challenges and interventions. Another parent added adaptability to courage. He said they were always adapting to what happened to their son, as was he. He used courage that he had learned from his son to start his own business, named after his son. His partner said: **“He has a special connection with his son and when he came in after work, they were always able to laugh together, even on the hard days, which made us forget about whatever went on during the day”**.

Determination is a bit similar to courage and was named as her strength by another parent. She told us how determined her daughter was, proving the doctors wrong many times. Her mother is now determined to keep her spirit

alive by involving herself in fund raisers for the Rare Find Foundation, talking to her and talking to everyone about her.

A father said his strengths are being caring and protective and creating connections. He said having the experience of having a child with a disability made them feel even more caring, supportive and protective of others around them. He said he continuously looks out for others who may need help, particularly those with a disability that others may just walk past. He told us how his son always brought out the best in people – he made people step outside their comfort zones and shared some anecdotes of strangers going out



of their way to help at times. He told us how his son brought people together and how he still tries to do that. All their other children have chosen caring careers which he believes is due to the influence of having him as a brother. His son gave sight to a stranger through organ donation even though he could not see himself. Through this his memory is honoured and his spirit kept alive. They now have a connection with the recipient who told them **“I have always heard the birds in the park, and now I can see them”**.

Parents in the group spoke about their need not only to talk about their child to others, but also to talk about death. They recognised in others a reluctance to talk about death and to acknowledge that death happens at any age, not just when people are old. Parents spoke about how it is difficult to share your stories when others are clearly uncomfortable and

this can change the way you interact with others. Some parents felt a responsibility to educate others about childhood death by talking about their child and their experiences of grief. One parent said that when you do share your story, it invites and gives other people permission to also share their stories. A parent who shares her story through a blog online has also found this to be true. She said, in the beginning this was **“strange and difficult, but I found people who connected with his story. It reminds me that I am not the only one thinking about him. Even people we can’t see or who have never met him might be thinking about him”**. She told us how a woman came to a fundraising sausage sizzle they were running and told them she had recently lost her child, and this was the first time she had left the house. She had come to get a sausage and talk about her child. **“It felt nice to be able to talk about death in a way that was not judgemental”**. Telling your child’s story is a way of honouring their life and educating others. Talking about the child within the family is also important, continuing the memories and helping other children feel they know their sibling or cousin helps to keep the child present. It is important to talk and laugh about the happy memories as well as talking about the sadness and pain of grief.



The group also discussed how they celebrate anniversaries – the sadness and the rewards. A parent talked about how she knew her son was no longer here, but she keeps thinking he will be coming back. This disconnect be-

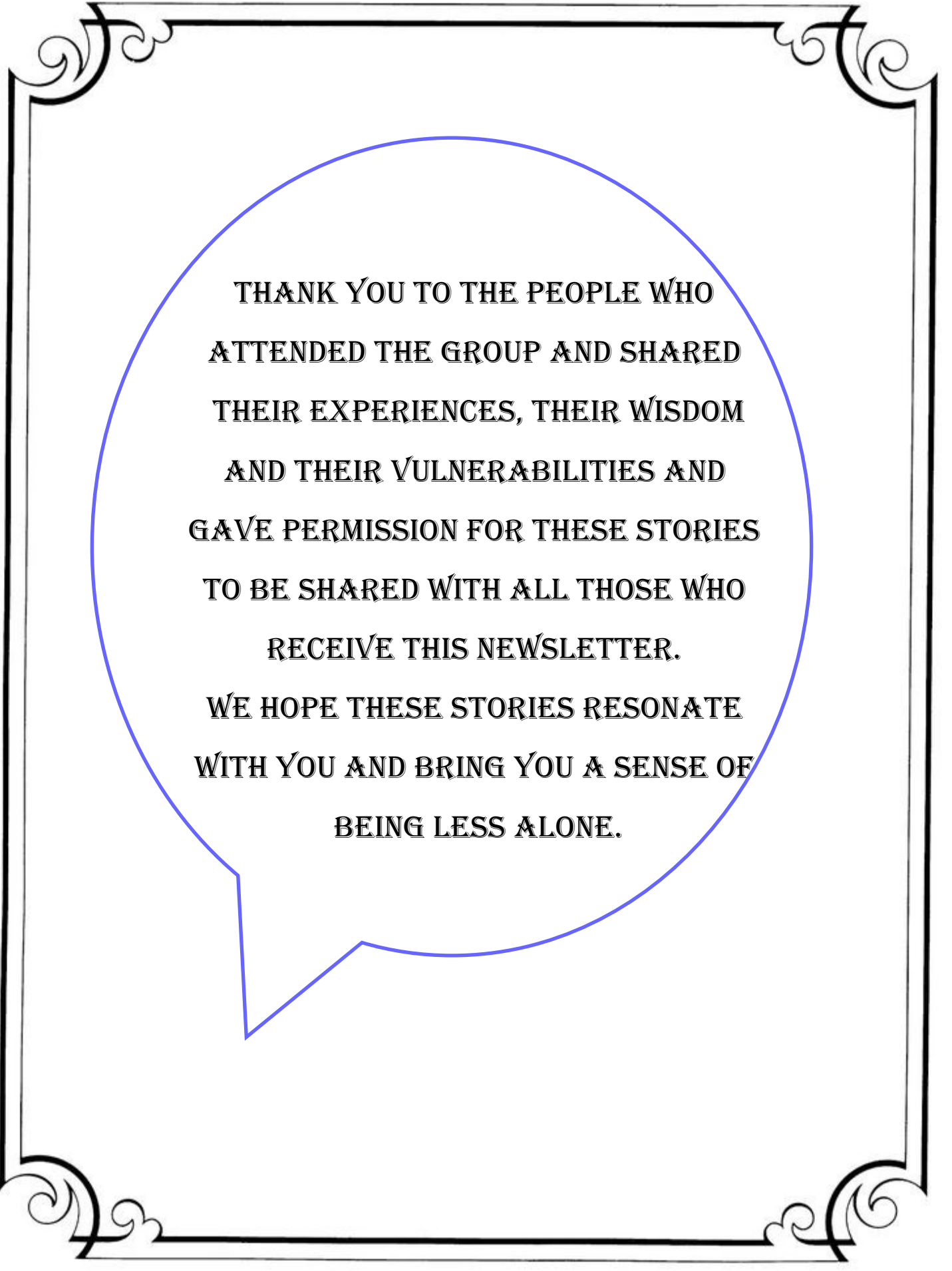
tween head and heart she described as head and heart smashing into each other. This difficulty parents have with their hearts accepting what their heads know, has been talked about in other groups and often comes to the fore when planning and experiencing anniversaries. One parent told us that their recent Father's Day had been sombre and emotional, but it had been important for the family to get together on this day. One family celebrate both Bereaved Father's Day as well as general Father's Day the following week. Most parents in the group mark their child's birthday with some sort of celebration. One parent described the party they created for her baby's first birthday, a birthday she did not live long enough to experience herself. A parent described how she starts preparing for her son's birthday a few months in advance. She thinks about how they will celebrate, what food and what cake to have, what he would like as a gift etc. She usually buys a gift for a child of the age he would be now and another gift for a baby the age he was when he died. She told us that after all the build up to the day, the day itself is both happy and sad. She said, **"The next day is almost worse than the day of the anniversary and there is an overwhelming sense of disappointment that he is not able to enjoy the celebrations, not able to eat his slice of cake and that the timeline of his life starts again"**. This timeline resets after each anniversary and reminds her that yet another year has passed. Ritual such as marking anniversaries, celebrating specific significant dates and doing things specific to your situation and

your child are important. Parents said some rituals make them feel like they are still doing the same things they would have been doing for their child and, by doing this it makes them feel closer to their child.

We concluded the group by specifically reflecting on the strengths the children possessed. We heard beautiful and powerful stories of children who were cheerful, always laughing, never complaining; children who were brave and resilient, proving the doctors wrong time and again; a child who loved the cricket and protested if it was turned off; children who brought many positives into the lives of their parents and families and who were powerful forces. A father described his child's greatest strength as forgiving. He said **"He forgave me and gave me permission not to carry guilt around. I learned how to move away from our negative emotions and focus on what we had gained. We couldn't change the event but how I feel about his story has helped me to be a better person and to move forward out of the darkness"**.

Parents reflected that in the group the child's story can be told and their lives can be acknowledged. They agreed that 'all children are powerful, our children are powerful, all our children lived'. In the group there is a feeling of being together in a place where they can feel each other's sadness and joy





THANK YOU TO THE PEOPLE WHO
ATTENDED THE GROUP AND SHARED
THEIR EXPERIENCES, THEIR WISDOM
AND THEIR VULNERABILITIES AND
GAVE PERMISSION FOR THESE STORIES
TO BE SHARED WITH ALL THOSE WHO
RECEIVE THIS NEWSLETTER.
WE HOPE THESE STORIES RESONATE
WITH YOU AND BRING YOU A SENSE OF
BEING LESS ALONE.

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 16th November 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:

What has happened to my brain?
The impact of grief on the brain and brain functioning

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 Meg Johnson 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



