

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER FEBRUARY 2023



## ***'SHARING THE JOURNEY'***

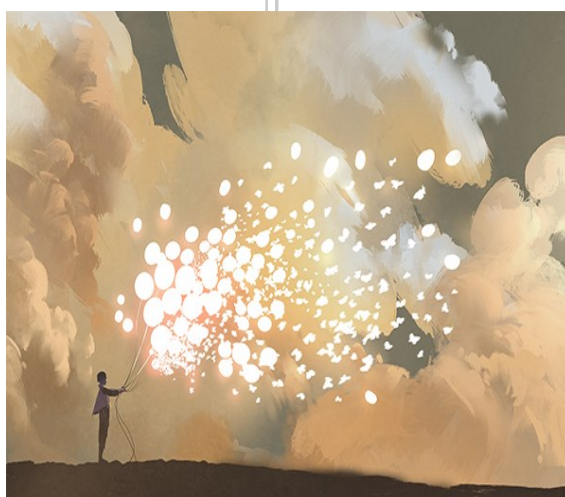
*Welcome to the first newsletter for 2023. The group was held face to face and welcomed 3 parents who had not attended the group before and whose children had died only months ago, as well as a couple familiar with the group. As always, the parents found much common ground in their grief.*

We began the group by learning more about the families and their children. One parent told us her child came to them as a foster child at 10 months of age and was only expected to live a few months. He passed away last year at the age of 14 years. Throughout his life he required care 24 hours a day. She spoke about the gap his death has left in her life and how she is trying to find ways to honour and remember him: “I

**find it hard to believe he is gone. I am trying to find things to remember and honour him”.**

Another couple told us that their daughter died in this hospital last year at just over 18 years of age. She had been a patient throughout her life and had many admissions and surgeries. Like the previous child, she had also required care 24 hours a day. Her parents told us she always knew what was going on and communicated using eye gaze technology. They said: **“I know she is at peace now and free, but we are broken”.**

Our other couple told us about their beautiful baby boy who died at the age of 10 months and 20 days. He had spent much of his life in



the hospital with some periods at home. As he was a baby and unwell a lot of the time, he also required constant care.

All the parents spoke of their child having times in their lives when they had been very unwell but had bounced back and how they had always known that there would come a time when they didn't but they always hoped that this was not that time – **“I knew this would be a reality one day , but she would always bounce back”**, and: **“I hoped he would have another surgery and be okay, but he wasn't”**.

All of these children spent a lot of time at the hospital and the parents spoke about how coming back to RCH the first time can be overwhelming – **“Everything, smells, carpark, signs, corridors, driving in – all these things are normal for most people but for us they can be overwhelming”**. However, at the same time coming back can feel like coming home. One parent said – **“Coming back to RCH is hard, but I feel he is here. The hospital is like home”**.

The topic for this group was about the journey – who is traveling with you, what can you share about how you are travelling on this difficult journey? All the parents in this particular group had experienced the need to provide a high level of care for their child throughout the child's life. One parent said – **“I was always caring for**



**him, then nothing..... Life goes on”**. All the parents in the group shared the experience of people not being there for them after their child had died – people they had expected to be on the journey with them often were not. They also spoke of losing a community when your child is no longer with you - **“When you have a community around you, they know you and support you. When your child dies, the support is gone”**. When you have a child with special needs you are surrounded by a whole community of people who either share the experience of having a child with a disability or who help to care for your child. When your child is gone, so are they. The parent whose child died as an infant told us that for her, the staff at the hospital were her community. She told us that she relied on them to affirm her as a mother – **“On the outside no one knew I was a mum, he didn't get to go to kinder or school. I would seek confirmation from the nurses and ask them ‘Am I a good mum?’ I was mothering him and being his advocate, saying what I thought and taking care of him”**. This mother told us that two of her sisters have been with her all through the journey, even though other family members have not. Other parents also spoke of family who could travel the journey with them, older children and partners and in one case, the child's birth parents. For this parent she felt her child's birth

parents were the only ones who truly understood how she felt as **“we have both lost a child”**.

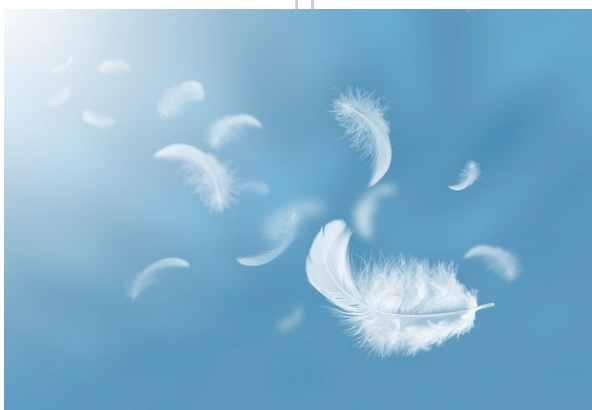
When talking about people who have some understanding of the journey, parents in the group also spoke about the insensitive expectations of others who cannot journey with them. The parent whose child was not her birth child told us that some other people did not acknowledge her as her child’s mother and thought she should not be as affected by his death. She also told us how hurt she was when some extended family members did not attend the funeral. Others told parents that their child was now ‘in a better place’, particularly when the child had lived with disability or illness. A parent said – **“He is not in a better place, his place is with me”**. Another parent spoke of the expectations other people had and continue to have of her. She told us that because she is still young, others expected her to have another child, or to get a job, go out, move on. The parent said she is unable to do that or to do other ‘normal’ things. She has come to a point in her journey where she is able to tell herself that she doesn’t have to listen to others or to be upset by their comments. **“I still feel**

**angry about the perceptions of others, I thought it wouldn’t impact on me but it did, but now I feel I can whisper to myself ‘don’t take on others expectations’ and they don’t upset me**

**as much. We need to let ourselves carry on doing what we want to do, regardless of what others say”**. A father told us that he felt that men’s experience of grief was not recognised or acknowledged, making being a grieving man a lonely place. Some parents spoke of the need to be brave for everyone else and how hard this can be.

The newly bereaved parents were exploring ways in their lives to remember and honour their children and were keen to talk about ways to do this. The two children who had died last year were both cremated. Both families found the presence of their child’s ashes powerful reminders of their child and felt a sense of their presence in their home. One family have the child’s ashes on her bed but are still seeking a special container for the ashes. Another parent said of her child **“I don’t want him to be in one place, I want him to be everywhere”**. She has placed some of his ashes in a teddy bear that sits in his wheelchair and has given some of them to his biological parents. The family have also

put some ashes under a tree in Bright where they would often holiday and gather in the shade of this tree. The other parents whose child was buried continue to visit the grave daily. All these children had special equipment and the parents spoke of their decisions regarding this equipment. Wheelchairs were very significant reminders of the children as they were almost part of their identity and parents



felt they would never give away the wheelchair their child used on a daily basis. One family have given away some of the less personal equipment to other families who will make good use of it. They told us that there were some pieces of equipment that NDIS would not fund or that they had to fight hard for and they wanted those hard won items put to good use. A mother told us that she still has the highchair in her kitchen and has his syringes and other pieces of equipment still in her cupboard where they always were. They have purchased and kept his feeding pump. She told us that sometimes she gets these things out to touch. She said **“There is no rush to do anything differently. Some people may think it is weird, but I’m okay with that”**. Another parent said, **“Everything at home reminds me of him, I have not been able to move anything”**. So many reminders everywhere. Another parent told us a beautiful story about the support and compassion of the Geelong football club. Her son loved footy and was a passionate Geelong supporter. She told us that Geelong never lost a match after he died. The club acknowledged him when they won the premiership, and she was asked to speak about her son on the radio. She said she will find the upcoming football season difficult without her son here to enjoy the matches with her.

The emptiness left by the loss of their child was expressed by all present. One mother told us: **“I have no direction now my child has died. Seven years on, what do I do with myself? I have lost a sense of purpose”**. Another par-

ent said – **“The worst time is being alone. I used to like time on my own, now it’s not okay”**. Another parent told us she is grateful she has another child who needs her time and attention – **“without her I wouldn’t get up, I would crawl into a hole”**. She also spoke about how hard it is to balance the needs of this child with her need to grieve. Parents spoke about the end of their child’s life. One parent told us how grateful they were for the special arrangements the hospital made for their daughter and the family when they knew she was nearing the end of her life. Although there were still visitor restrictions with COVID, the whole family was allowed to come in and spend time with her, she was even allowed to have her dog with her, and it slept on her bed through those last days. She went when she was ready – in her own time, surrounded by those she loved. Another parent told us how hard she found it when a referral to the palliative care team was made. **“I felt I was giving up on him, no amount of saying I didn’t give up on him helped. I can’t get past it. People said I was a good mum, but if I’d been a good mum, I would have gone with him. I never left him alone”**.

Parents talked about the multiple and ongoing losses brought by the death of their child. There was most obviously the loss of the child and all that went with them – **“I miss him, miss touching him, even nappy changes”**. The relationship a parent has with a disabled child has an intimacy about it that is different to the closeness they may have with an able child. The other losses in-

clude loss of the caring role, loss of community, loss of identity as a parent and loss of future hopes and joys. A couple told us that their daughter was very excited about becoming an aunt and her brother was looking forward to introducing his child to his sister. Sadly she died before the child was born. New births can be triggering for many bereaved parents, the joy of a new life, a new child in the family, always tinged with sadness for the child that is not there. Another parent told us that her mother had died not long after her child and also that they had never had a Father's day with their child. Losses don't stop with the death of a child.

The parent who had fostered her child said "I don't see his face in the faces of my children or my husband. I only see his face in the faces of his birth parents".

For two of the families, the Christmas just past was their first Christmas without their child. One parent told us she had sent letters to all the family giving them a task – to perform a random act of kindness for someone to remember the child. Everyone embraced the challenge and came up with some creative and meaningful ideas, all of which keep the child's story alive as each recipient of the random act of kindness also received a letter outlining the child's story. Several families had a star named after their child. Although they found it difficult to identify the star, they found comfort knowing their child's star was there. One child's birth-

day was early in the year and they released balloons on her birthday. Another parent still has a cake on her child's 'month birthdays' – ie a cake for him each month.

When talking about the things parents do to keep their child present in their lives and to honour their child's memory, a parent asked about 'signs'. One parent said they walked out the back of the house after their child had died and there was a bright star in the sky they had never seen before. The star is still there – is this a sign of their child's presence? A parent asked, "**How much is too much**" in relation to signs. The parent who has been living with grief for several years responded: "**Anything you choose to believe is a sign, is a sign – a star above the grave, a dragonfly, anything that has meaning. If you believe in God, there are no limits, so if you believe it is a sign from your child, why should there be limits**"? One couple told us that they came home near Christmas when the tree was up and their child's glass bauble had fallen from the tree and rolled to the door. The delicate bauble was undamaged – they felt this was a sign from their daughter and wondered about the

meaning of it. Another parent writes about her child everyday on a Facebook page. She said: "**Some days it is short and some really long.....some people say, it's been too long. They don't understand**".

There were parents in this group who



they liked coming back to the RCH where their child spent so much of his life. They know that you don't have to speak, you can just listen if that is what you want to do. They acknowledged that coming to the group can be anxiety provoking, but **"If it didn't bring comfort, we wouldn't come"**. The group can be a shared connection as parents all feel similar things in a way those who have not lost a child do not. Another way many parents seek connection and understanding of their grief is through literature. A parent told us he tries to find things to read about child loss and finds these stories help to connect to other grieving parents. Other parents also look for literature for both themselves and their other children.

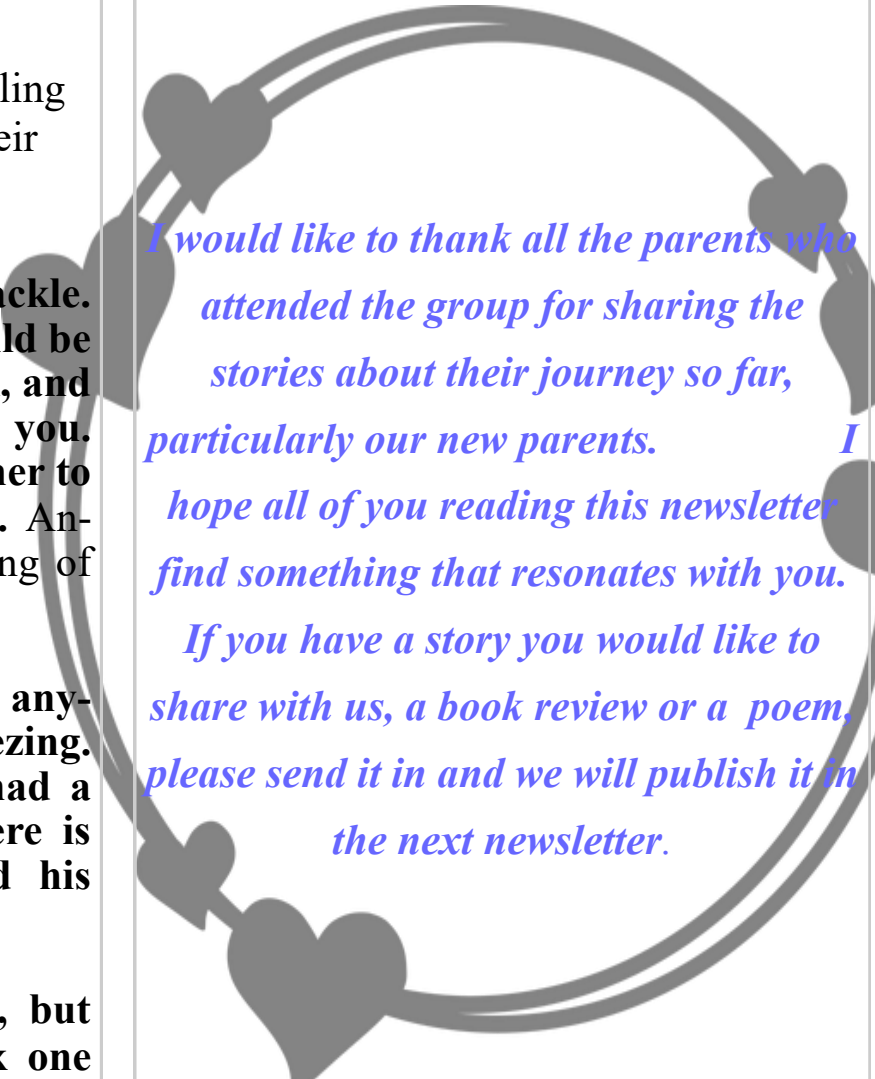
We finished the group by parents telling the group one special thing about their child that brings them joy.

**"Her laughter, it was like a cackle. She would laugh so much she would be crying. The laughter was random, and she would laugh at you, not with you. Often you would have to remind her to breathe when she was laughing"**. Another favourite memory was thinking of her big eyes.

**"His laughter. He would laugh at anything, random things and sneezing. Now sneezing can be sad. He had a big laugh. I miss that, now there is silence. I loved his laugh and his smile"**.

**"He looked exactly like his dad, but blonde. I find it difficult to pick one**

**memory – I loved everything about him, he was magical. He would say "mana" (mumma) with his raspy voice and "dat" (dad). He loved being outside in the wind"**. His father also shared his favourite memory. **"The big smile on his face when we came into his room at the hospital in the morning"**. His mother told us that when he was in hospital, they couldn't always stay the night but when they came in the next morning they would race each other down the hallway, jostling each other, trying to be the first in the room and see that wonderful smile.



*I would like to thank all the parents who attended the group for sharing the stories about their journey so far, particularly our new parents. 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 16th March 2023**  
**7.30pm—9.00pm**  
**The RCH Foundation Board Room**  
**Level 2, 48 Flemington Road**  
**Parkville, VIC 3052**

Please join us to discuss the topic:

**“Life after Loss – how does this change over time, how do you/ can you find purpose and meaning in life?”**

**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 Denise Browne 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**



