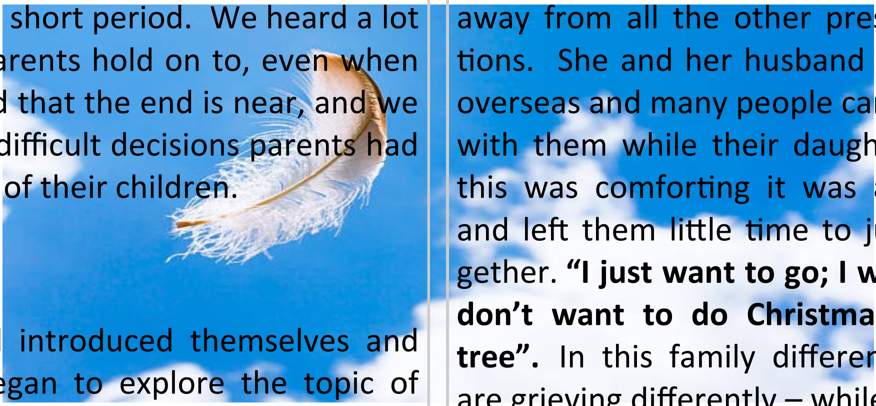
FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER NOVEMBER 2023

Travel and Grief - Can vacations help with Grief?

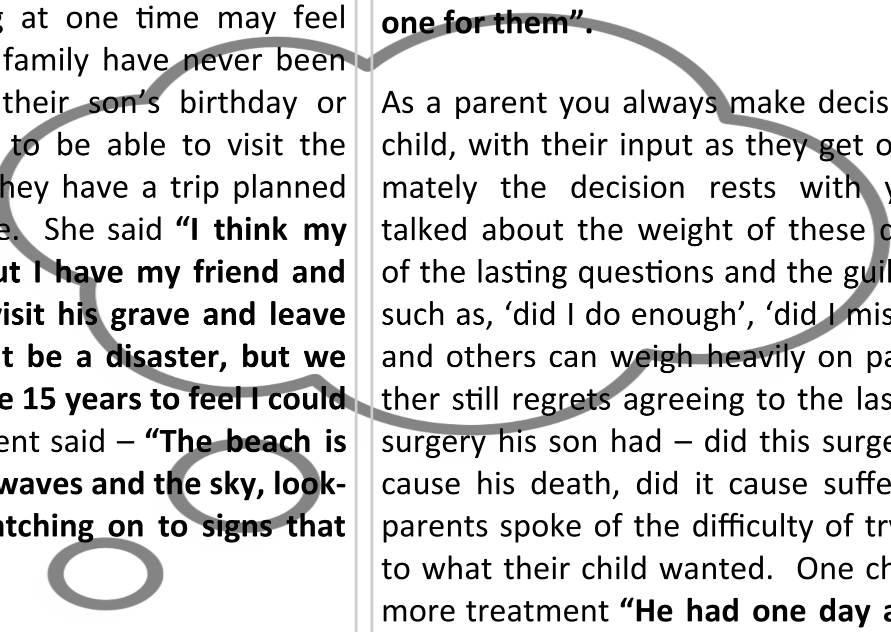
The November group welcomed several newly bereaved parents attending for the first time, as well as parents who had been bereaved for longer periods. The age of the children ranged from infancy to teenage years. There was both variety and commonality in the stories and experiences of the families. We heard the heartbreaking stories of children fighting an illness – fighting the monster, for many months, having a period of good health, only to relapse and lose their lives in a short period. We heard a lot about the hope parents hold on to, even when they are being told that the end is near, and we heard of the very difficult decisions parents had to make on behalf of their children.



Grief and Travel

After parents had introduced themselves and their child, we began to explore the topic of Grief and Travel. One parent did a lot of travelling with her son when he was living. They now try to go back to the places they have been with him – **"We take a bit of him with us and leave a bit of him wherever we go so he will always be there. I like going to places where he was because I can remember him there. I can't go to places he has never been".** She also spoke of feeling guilty that she can now get ready to go on a trip in what seems like just a few minutes - when her son was alive it took a long time and lots of planning to get everything he needed ready for travel. Another newly bereaved parent told us she has booked a holiday for the family. She said people encouraged her to get away with the family to just have family time and be away from all the other pressures and distractions. She and her husband have large families overseas and many people came to visit and stay with them while their daughter was ill. While this was comforting it was also overwhelming and left them little time to just be a family together. **"I just want to go; I want to get away. I don't want to do Christmas; I don't want a tree".** In this family different family members are grieving differently – while the mother wants to go away the father said – **"I just want to hibernate; I am empty and lost and it doesn't feel real"** and the children are not keen to go. They will go anyway and see how it works out.

Another parent shared her experience of going away right after her son's funeral. She said they didn't go far and the first couple of days were okay but then she just sat in the hotel room and cried – **"I said I wanted to go home, why should we be paying for a hotel room to cry in when I could do that just as well in my own home".** They abandoned that holiday but have travelled with their younger children since then. They always take their son with them; they have a bear identical to the one he had in hospital, and they carry his hospital wrist band with them. They include the bear in photos while they are travelling. She said they always see signs that he is with them. She told the group that sometimes you just try something, and you don't know how it will go until you do it. You always need an exit strategy, and something that feels wrong at one time may feel right at another. This family have never been away at the time of their son's birthday or Christmas as they like to be able to visit the cemetery. Next year they have a trip planned that will be at this time. She said **"I think my heart will be ready, but I have my friend and my parents who will visit his grave and leave fresh flowers. It might be a disaster, but we will try. It has taken me 15 years to feel I could do this".** Another parent said – **"The beach is helpful; looking at the waves and the sky, looking for feathers and latching on to signs that he is there".**



Many of the parents in the group had other children, some alive when their sibling died, and some born subsequent to their sibling's death. Some of the parents talked about their concerns about their other children and how they were coping with their grief. One of the children was an identical twin. Her parents told us that the twin is very angry and has changed since her sister died – **"It is like a piece of her has been ripped away. She won't sleep alone anymore. The teachers at school say they are keeping an eye on her".** Her sister was always looking out for her and now she is alone. She will not talk to a counsellor and nor will she engage in any sort of non-talking therapies such as art. Another parent told us their younger child has also had a significant deterioration in their mental health – something they have always struggled with. They have spoken of taking their own life and they can't leave them on their own just now. It is an extra layer of grief when you have to watch your children going through their grieving process and you feel helpless. Everyone needs to travel their own grief journey. One parent said; **"I feel they lock their pain in a box, the pain is locked. I feel all my child's boxes are unlocking at the same time".** We want our children to process their pain and their grief now, but someone in the group pointed out **"We don't have a timeline for us, so we can't have one for them".**

As a parent you always make decisions for your child, with their input as they get older but ultimately the decision rests with you. Parents talked about the weight of these decisions and of the lasting questions and the guilt. Questions such as, 'did I do enough', 'did I miss something' and others can weigh heavily on parents. A father still regrets agreeing to the last open-heart surgery his son had – did this surgery hasten or cause his death, did it cause suffering? Other parents spoke of the difficulty of trying to listen to what their child wanted. One child asked for more treatment **"He had one day at school – a special AFL day and he was so happy. He said he wanted to ask for more treatment, he wanted more days like that one".** Later the same child begged to stop the new treatment – he had had enough. Similarly, another child begged to be sent home from ED towards the end of her life. She did not want to be admitted to hospital again. She wanted to be home amongst the familiar sounds and smells of her own home and family. Her parents had not told her she was dying but after this they questioned, did she know? They also worry about their decision not to tell her and question if that was the right thing to do. Another parent whose baby suffered some complications after heart surgery knew when she looked at his MRI that they had to make the decision to withdraw treatment. She said – **"It was the best decision for him but the worst decision for us".** Parents questioned if they made decisions for their child, or for themselves. One parent said **"I grappled with comfort care. There were so many machines, they could keep him alive on the machines; but why am I continuing? He didn't leave the hospital, he didn't feel the sun or the wind on his skin. Why am I pushing? I need to let him rest. But where is the line, how long should we fight? It is the hardest".** Another parent told us; **"I said I would never keep him here for me, but when it came to it, I wanted him with me".** As one parent said: **"We are the parents, we are meant to look after them. The only thing you can do as a parent is to make the best choices for them at the time……You hang on to hope. You use the information you have at the time. There is no crystal ball".**

Parents always hold on to hope, and the decision about when to stop treating was an agonisingly difficult decision for many. Some parents reflected on their feelings when palliative care was suggested. Some parents saw this as giving up hope – **"A counsellor told me to start planning her funeral and I told her to fuck off – I still had hope. I still wanted her to live….I wanted to smash things. I had hope".** One mother feels guilty that she made the decision to accept palliative care and feels this meant she gave up on him – **"I feel I need to apologise to him and try to remember the good times. It is an ongoing battle".** Another parent shared her reaction when a nurse suggested comfort care for her baby. She explained that until she got the diagnosis she had no idea the condition even existed. **"We were hopeful, and then we were distraught. I am embarrassed to say, I hate the nurse who told us he was going to die…… It's too much. How are we expected to be okay? What am I supposed to say? I don't want to take home a cast foot, I want to be with my child".** The last things parents said and did with their child are so significant. One family went on a overseas holiday in the window of their child being well between the end of treatment and relapse. Their daughter had a wonderful time but returned to the devastating news of her relapse. At the very end, her father told her that she could stop fighting, he and her mother would be okay. She slipped away shortly after that. **"I lied to her, we are not okay, how can we be okay"?** Another parent had her child sleeping in her bed for 3 weeks prior to his death. He died the night she moved him back into his own bed. She wondered if that is what he wanted.

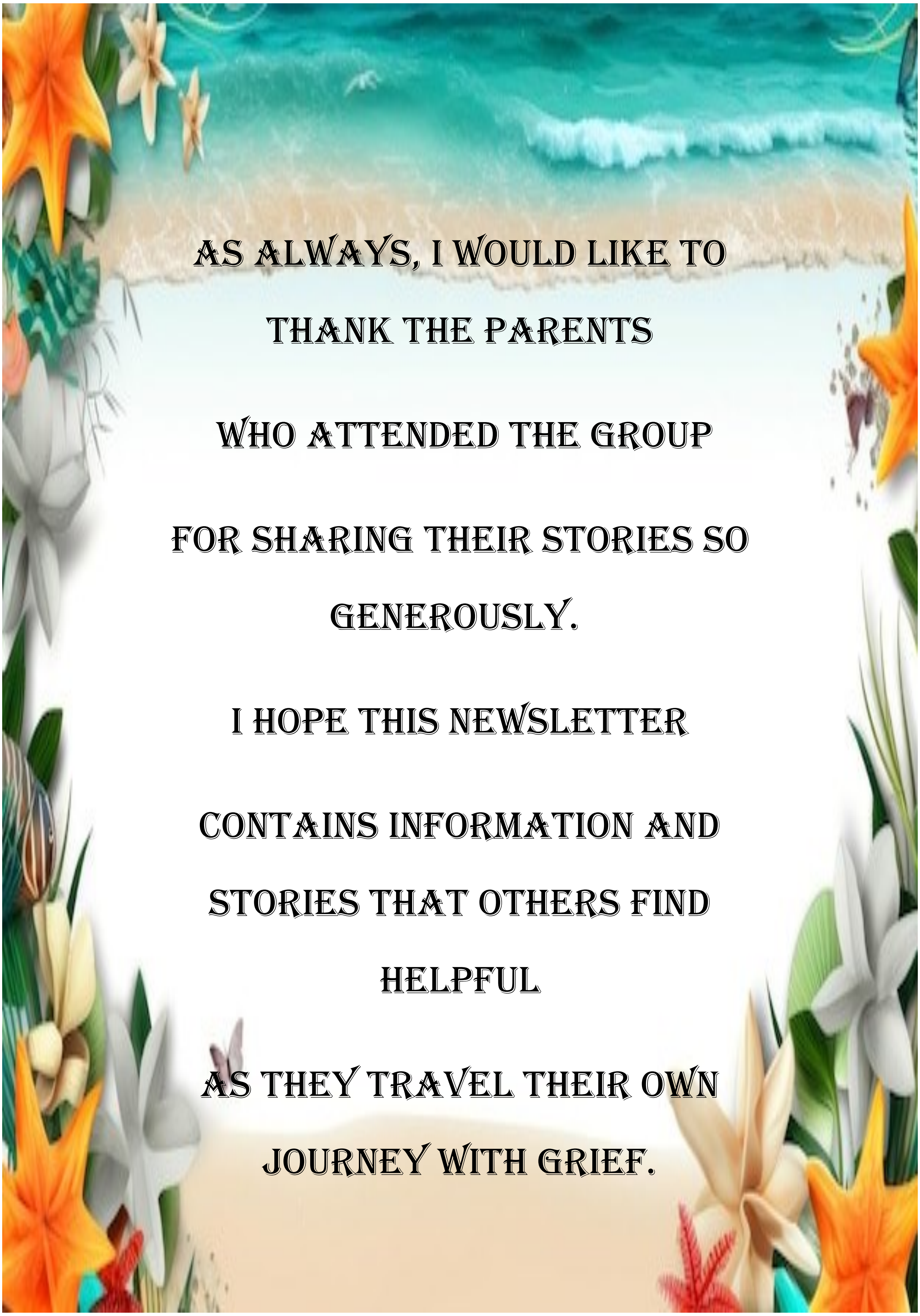
Some parents spoke of how they prayed for their child's recovery. Some had many people praying for them, sometimes from around the world. For some parents the loss of their child also resulted in the loss of their faith, some had

their faith tested, while others continued to find comfort in God. A father told us; **"I prayed every day. Prayer is power. I thought it would be enough; obviously it wasn't. Having belief kept me sane. I have anger and rage; how could this happen to an 11 year old? I still believe and go to church everyday, it keeps me from losing my mind".** A mother said she did not have any faith before she had her child, although she had been brought up in a religious family. Many of her siblings have married into different faiths, including Moslem and Orthodox. She used to be angry when they told her that her child was in a good place and that she should have faith, but now she has changed her attitude: **"It used to anger me, but after a while it was comforting – if they believe he is in another place, maybe that is nicer. Why should I feel angry"?** Another mother still believes in God but is now scared of him. The belief that he knew how much she wanted and loved her child but he still allowed her to die has made her feel that he is cruel and not a loving God at all. She no longer goes to church and wants to avoid God's attention. A mother said; **"If I absolutely knew there was a heaven, I would go and be with him".**

Surviving the months and years after a child's death can be made much more difficult when others around you have unrealistic expectations. One mother felt that her friends and family gave her a week to grieve then expected her to be back to 'normal'. **"I am learning I don't have to be nice. I tried, but I realised I was doing it to make others feel okay. I don't have to pretend and smile and be fine…..I put out a message 'I am going offline'. I am hibernating…..I wake up and shower, sit with my husband and son and I am happy".** Others also talked about focusing on immediate family and not being involved with things outside the family. They spoke of their triggers – seeing other babies, talking to people, friends or relatives who are pregnant, hearing ambulance sirens, passing certain places and many others. Avoiding triggers when you can helps, even if this risks others being offended. A more experienced parent said it is okay not to celebrate or to do things with family. She told us about her first Christmas after her baby died and how she changed her mind about having a Christmas tree at the last minute but took it down again at the end of Christmas Day. She felt her son would have wanted a Christmas Tree. The feeling of waking each morning and thinking it is all a dream was common in the group – the disconnect between head and heart. How do you reconfigure your thinking about your family when one member is missing? A parent told us she was booking tickets for 6 when organising a holiday, meal reservations for 6, everything for 6, even though one child was not there. Other parents still buy a football membership for their child – "**Everything just rolls over".** You do what feels right over time. A parent told us their son's name is still on their medicare card and ambulance membership. Another was told that when they issued a new medicare card for their next child, the name of the deceased child would not be on the card but his number would not be given to the next child – there would always be a number missing. The birth certificates of the children have their brother's name on them but he is listed as 'deceased'. Parents commented that it is good to be prepared for these things as otherwise it can be a shock.

Two families had also experienced the shock of their portal access to their child's medical record being removed – fortunately this can be reinstated.

Moving through grief is hard, and there are many expected and unexpected challenges along the way. Hearing each other's stories can also be hard, but it can be affirming to know that others have also had experiences like your own and that even in this group there is a diversity in how parents react to their experiences, and that is okay.



AS ALWAYS, I WOULD LIKE TO
THANK THE PARENTS

WHO ATTENDED THE GROUP

FOR SHARING THEIR STORIES SO
GENEROUSLY.

I HOPE THIS NEWSLETTER

CONTAINS INFORMATION AND
STORIES THAT OTHERS FIND
HELPFUL

AS THEY TRAVEL THEIR OWN
JOURNEY WITH GRIEF.

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 14th December 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:

Dilemmas of the holiday season - planning for spaces and connections to sustain you and acknowledge your grief.

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 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