FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department



NEWSLETTER DECEMBER 2021



In this, the final group of the year we had three families attend, two for whom this will be the first Christmas without their child. As the end of the year approaches with all the chaos and expectations of the season we discussed how to keep the children present at this time and how to navigate the season. We began by sharing the symbols reminded parents of their child. One couple told us about their beautiful infant son and showed us the crystal created to enclose his ashes. They also planted a legacy tree in his honour and will watch it grow. They said: "We watch it grow and one day it will be big enough for us to hug - I can't wait for that day. We miss him a lot". For these parents the rainbow holds special significance. They played 'Over the Rainbow' to their son in his final moments.

Another parent told us that she had always referred to her daughter as; "my dandelion child. When she was born, she had no hair, and it took years to grow. When it did, she had fine white fluff in little curls and when the sun shone on her from behind, she looked like a little dandelion. When she was diagnosed, I told her dandelions were unkillable". She also told us

that dragonflies are another significant symbol as both she and her daughter were born in the year of the dragon. She said: "Every time I see a dandelion, I pick it and plant the seeds".

The meaningful symbols for the other parent in this group are the moon and superman. "We had 2 favourite books for him – 'Guess How Much I Love You' and 'Mummy's Most Loved Monster'. We read them to him every day during the pregnancy and after he was born. I would always say -'Love you to the moon and back'. On our way home from the hospital after he died, in the early hours of the morning the moon was huge above our house and we said 'that's our child telling us he's okay". This parent also shared the story about the superman connection. "My sister bought him a superman onesie - it was way too big for him and she kept telling him that he needed to fit into it.....We buried him in this. Our family and friends know all this, and they buy superman and moon things for us – our 2 symbols".

Many bereaved parents get tattoos of the symbols and images that represent their child, thus

keeping the child's memory close but also with a visual representation of their love and loss. One of the parents showed us a tattoo on her forearm of a dandelion with the seeds turning into dragonflies as they blew from the plant. Another couple spoke of their plans to get tattoos - using images of their baby, holding his hand, his name and date of birth, motifs of gum leaves from his blanket.

Some of the parents had bakeable clay and they made their symbols while we continued to talk in the group. One parent told us she intends to let her other 2 children make a Christmas decoration each with the clay. Every year they buy a decoration for their brother but this year they will make one.

The parents in the group talked about how they were planning to spend Christmas and how they anticipate keeping their child present. One parent showed us a lovely photo of their child in a Christmas decoration. They keep this with their Christmas tree. They are trying to create traditions that they will carry on with over the years. Another parent talked about how some of the things they did on that first Christmas have persisted and become part of the family tradition, but others have changed over the years. As this child was born only 2 days before Christmas his birthday, Christmas and the anniversary of his death are all quite close. The family have found ways of marking each of

those days. The birthday is a celebration: "His birthday is okay – it is a celebration that he was ours and he chose us. We go and stay in the city and do things he would have liked to do. We go to the cemetery on Christmas Day and exchange presents with him". She explained that as going to the cemetery is so important for the family, they always host Christmas and do not leave Melbourne that day. They feel very fortunate that



their child was able to experience Christmas in his short life and a photo taken with Santa in the RCH on Christmas Day is very precious.

Many families find celebrating Christmas in the early years following their child's death almost impossible. One parent told us that she was going to spend Christmas with her family interstate. She is sad that she will not be able to visit her daughter's grave on Christmas Day and won't be home to mark her daughter's birthday on the 27th December. She said: "There is no tradition.....I am dealing with



it by ignoring it all". Sometimes that is all you can do to begin with. Another parent told us about her first Christmas without her child. how she has always loved Christmas and how excited she was when her baby was born a little early, just before Christmas so he could celebrate that first Christmas. "The first vear I was not going to have a tree but just before Christmas I decided that he (child) got here early to celebrate Christmas so I had to celebrate it. We put up the tree 2 days before Christmas but as soon as Christmas was over I had to take it down. The second vear his brother was here which made it a bit easier. The Christmas thing doesn't phase me as much now. I feel as though I have my Christmas joy back. He is my Christmas star". She also told us how hard it was coming home from hospital without her child to a house decorated for Christmas. The parents who have planted the legacy tree will always visit the tree on Christmas Day.

How Christmas and other significant occasions are experienced is always influenced by the attitudes of those closest to you. Those in this group all felt their family were understanding of their grief and what they may need in the coming weeks. One parent has

discovered that his sister is pregnant. said: "It hurts knowing this. We are happy for her, but the timing is hard. It is hard knowing our son will never grow up with his cousin". Another parent told us how she couldn't face seeing her very young cousins on their first without Christmas their child. She told us her aunt had been very sensitive and had arranged to spend that Christmas with other side of her famicerns. Although everyone in the group believed their family would be sensitive, they still felt they did not know if they would be able to be with the family for the whole day – "We will see our family, but we don't want to put pressure on ourselves.....We feel lost. We just need to take it slowly". Even when you have supportive family there are always going to be tricky moments with family and with friends. As one parent said – "We have had friends who have disappeared. The friends we thought might support us didn't. It was surprising......We had tricky moments". This parent reflected that at the time they had their child, few of their friends had children and this probably contributed to their uncertainty as to how to support them. She was also aware that her own family who lived close by were able to be more supportive as they saw them frequently and could see how they were managing, but family who lived further away only had phone calls to go on. One parent commented on how she hates the 'how are you question'. She said, "How do you think I am"? Another parent told us that even when you answer that question honestly some people just ignore the response and continue with the conversation as if everything was

ly without her needing to express her con-

tion as if everything was normal. This is also very frustrating.

A father in the group told us that his boss, who has known him for many years and is almost like a father to him commented that it was hard for him (the boss) having him away from work. comment was made less than 2 months following the death of their child. "I went and spoke to him. I told him how I was feeling, the appointments we had to go to, I told him everything. It



got him thinking that there was more to it. He was then able to understand the grieving process". It takes great courage to tell someone what you need and how you are truly feeling but it can be very rewarding when you do if the other person listens and changes their behaviour. This was also discussed in relation to including the child's name on Christmas and other cards. One parent told us that she told people she wanted her son's name to be included on the cards and she always included his name on any cards she sent. It was therefore especially frustrating when his name was not included, but on the other hand it brought her great joy when she opened a card and saw his name. His two younger siblings always include his name whenever they write a card and she sometimes wonders how this is received by their friends. One parent said - "You have to make it clear to others what you need. It doesn't seem fair had taken over 1000 photos of their child during his brief life but at this time it was too overwhelming to even start to go through them. Another parent said it was her aim to have a book of her child's life done for each of her cousins by Christmas, but she hadn't managed to even begin yet. Another parent reassured her that these things take time and she had taken 5 years to complete a scrap book of photos of her son which she had hoped to have completed by his first birthday. These things take time and cannot be rushed.

Other things also take time — taking the car seat out of the car, organising photos, sorting through clothes and possessions and many other things. It can be hard not to feel pressured by other people's timelines and stick to your own. One couple said: "We haven't taken his car seat out of the car yet. Other people probably think we are crazy when



with everything else that is going on. It's one more thing that sucks about it". One family have had cards made with his tree on them and his name. "We hope the cards will let people know that we want his name on cards".

Parents in the group spoke about the photos that they have of their children and how they use them. One family had photos taken in the hospital by the Heartfelt photographers. They have used these photos to put on their wall and around their house. They told us that they

we say we can't pick them up because we have the car seat in the car and there isn't room. Perhaps it will stay there until we have another child who will use it". Apart from photos there are lots of other mementoes and memories parents have. "The RCH gave us a memory box with all his things—they did plaster casts of his hands and feet. They are so special, you can see all the little lines in his feet. They put the thermometer they used for him, his BiPap and all the things that they had for him. It is all now in his memory box with rainbows in

it".

The other significant day coming up is New Year's Eve/Day. For some families the changing of the year can feel very significant, particularly the first year. When the year that your child died in has past, then you are living in a year that your child never did. As one parent said - "I'll be saying our son passed away last year". One parent told us "Winter was hard she was missing it, then that made me think about all the firsts without her. I have found them very difficult". And for another family - "We had plans of what we would be doing as a family, camping as a family, things we wanted to do....now none of that will eventuate. It is hard. We take each day as it comes. We will be where we need to be (at the end of the year). We might want to get away from it all. I feel blank, not sure how to feel, what's right or wrong". parent said "The lead up to important dates is harder than the actual day...... Now it's the unexpected things that are hardest. It is often doing things for the first time with one of the other children that I would have been doing with him, things I had not thought about since I was pregnant with him. It cements what **I had missed out on".** Other parents also talked about what triggers their grief such as seeing other babies in prams or others holding their newborns – things you cannot predict or prepare for.

Those who had made symbols showed them to the group – colourful rainbows and

superman symbols. An interesting fact about rainbows is that when you see a double rainbow the colours are reversed in the second rainbow – like a mirror image of the first. For those for whom this is the first Christmas without their child and who are still navigating all the firsts, it is important to remember that things take time to evolve, traditions to develop and that things develop and happen over time. There are no road maps, no manuals to follow and things have to be done at the pace of the individuals concerned. Find people who give you energy, not who drain you. As one parent said: "If you need to cry, cry. Everything will fall into place......I talk to him all the time – is that crazy"? "So nice to connect with others in a similar situation. Life does evolve. It is refreshing and reassuring to know we can get through this". Talk to your child if that feels right, cry if you need to cry, leave the car seat in the car and the room untouched, visit the cemetery, hold him in his crystal, hug his tree, spend time with family and friends or alone if that feels right, and talk about your child to whomever will listen. Go well this holiday season and remember you are not alone, there are others who travel this journey also.

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 (Via Zoom)

Thursday 17th February 2022 at 7.30pm

Please join us to discuss the topic:

TBA

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 ——for scribing parents' statements.

Also to Marina Puljic for ensuring the newsletter is formatted, collated and distributed to interested people

Social Work Department, RCH





Parents' Bereavement Support Group Meetings 2022

Family Bereavement Support Evening Group will continue to be (Via Zoom) until further notice

Time: 7:30 - 9:00pm

Monthly Parents' Bereavement Support Group

February 17th

March 17th

April 21st

May 19st

June 16th

July 21st

August 18th

September 15th

October 20th

November 17th

December 8th (please note this is a week earlier due to Christmas)