

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER MARCH 2023



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

Welcome to our March bereavement newsletter. The group was again held face to face, and we discussed the difficult issue of Life After Loss. In the group we had parents who were quite recently bereaved - **“We are in the early part. It’s just coming up for 4 months”**, and parents who were 7 years into their life after losing their child. Whether your child died 10 weeks ago or 7 years ago, the grief and sadness remain real and devastating. One parent said life after loss is **“challenging in every way you can think of”**. She said she thinks it doesn’t really get easier but there is a shift. **“It’s not easier 7 years later, but there is a shift.... When he passed away, I looked weathered and distraught, but now I can put on a face”**. She said she had developed a dark sense of humour, but she has also learned how to support others in their grief and knows what not to say. She also told us, although she doesn’t believe in God, she now realises that people want to make you feel better when they talk about her child being with God, or in heaven. She said she understands now that some belief systems can be very comforting and at times, she almost regrets



that she doesn’t have such a belief system. Parents spoke of the difficulty they have coming to terms with the reality that their child is really gone. They find it hard to truly believe that this has happened. One parent said, **“it feels like it is temporary”** and another commented **“it feels like it is a dream, but it’s reality”**. All the parents spoke of the difficulty of making sense of the loss of their child, even 7 years on: **“I can’t process it – we had a baby...and he died.....Does your brain stop you going there? It doesn’t feel real, even after 7 years. I feel I am in a constant state of trying to make sense of it”**. A parent told us she is trying to understand why he died, as she knows how he died.

In talking about loss, the group talked about how prepared they were for their child’s death and at what stage they knew their child had a shortened life expectancy. Did knowing your child was going to die make it easier? One child was diagnosed with his serious heart condition before birth, so his parent had always known he was a sick child. Another parent had fostered her child

when he was a baby, knowing he had a limited life span – he lived many years more than was predicted. Other parents did not know until their child was about 12 months old that all was not well. It was some time before genetic testing revealed what condition she actually had. As this condition is regressive, they always knew she would not live a usual life span. Knowing this, however, did not make losing their child any easier. One parent said: **“You think you’ll be ready, but you’re not”**. Another mother said – **“I was always realistic about decisions for his life. I used to think ‘what’s it going to be like to live without him’ but it never felt like he would really die..... Then you have to live without them.”** All the parents had the experience of being told their child was close to the end of life more than once, sometimes months or years apart, so it was very hard to believe that the time had truly come. All the children had died with those who meant the most to them around them with one even having her dog with her in the hospital in her last days. One parent questioned if she had done the right thing in having her youngest daughter present when her brother died, as she was highly distressed by his death. She reasoned that if she had been absent when the rest of the family were there, she would have felt excluded, and this would have been even more difficult for her in the long run.

Along with the difficulties of trying to make sense of what has happened is the questioning of your decisions before the child died. One parent said that she always made decisions she believed were in her child’s best interests and she trusted his medi-



cal team, but she still finds herself second guessing – **“Did we make the right decisions, did we do the right thing? I can’t help but worry, did we do the right surgeries?..... Did I miss something. Should I have gone down a different path”**? Even with all these questions, the parents felt that their child’s medical team always made decisions in their child’s best interests. One couple expressed regret that their child did not live to see the possible benefits of a new drug becoming available to improve the lives of children with her condition. For one parent, her regrets were not only related to decisions she made about her son, but also to the impact on her younger daughter of having a brother with such high needs. She said – **“My 13-year-old daughter is struggling. She is getting counselling. She was doing better but has gone down again since his death. What have I missed with her because of him”**?

A father in the group, when talking about life after the death of his child said; **“You find out who your friends are and who your family are”**. This statement struck a chord with the other parents in the group, with many having experiences of those they thought would be the most supportive just not being present and others they had not even been overly close to stepping up. For some parents, family has been very supportive and understanding, particularly their young adult children but for others family has been more problematic. One parent described the difference between how she and her family respond to distress and how her partner’s family respond as a clash of cultures. She told us her husband’s family do not talk about feelings while her family are big talk-

ers. **“My husband’s uncle told me not to tell people about my pregnancy because we knew he was sick, and he may die. He questions why I still go to the cemetery, and he won’t talk about my child. His attitude was very different when his father died. He goes to the cemetery and talks about him. He also now talks about my child”**. One parent simply said, **“Families are hard”**. There are others who were in your life before, who you lose due to the changed circumstances, but some continue to keep in touch. Some parents told us that their child’s teacher, coordinator, and bus driver all randomly message or send emails. They had lots of messages around their daughter’s birthday and Christmas. All the parents present had been very involved with the hospital and spoke of their attachment to staff who cared for their child. One parent said of hospital staff and the special school coordinators: **“No matter how much you want to hold on to people, you have to let them go.....they have to look after other kids”**. It was acknowledged that it is hard for others who have not experienced such a massive loss to understand how it feels being in your shoes. A parent who had fostered her child as a baby and throughout his life, said she found her grief is mirrored by his birth parents who have always been part of his life.

Something parents want from family and friends is a willingness to talk about and to listen to them talking about their child. This does not always happen. One parent said that even from the very beginning, no one wanted to talk about him. She also said: **“We can’t make any more memories, so I want to talk about and remember the ones we have”**. The sisters and some friends of one of the parents send her messages hoping she has a gentle day etc. but they don’t talk to her and invite her to talk about her child. She said: **“No one really asks how you are going. I just want to have a proper conversation about him”**. There are also lots of very unhelpful comments such as - ‘he was only a ba-

by’, and ‘you didn’t give birth to him’, suggesting the grief should not be so intense. As one parent said – **“I don’t think these things ever leave you – it’s painful”**.

A father told us about how seeing the school bus come past the house after picking up a child from around the corner really triggers his grief. Other parents also talked about the things that can do this for them. One parent was in Kmart and walked through the boy’s wear section. She told us how incredibly painful this was for her as she could not help thinking about the clothes she would have bought for her son. She says she asks herself. **“Why am I torturing myself, but everything means something, everywhere there are memories of him”**. She spoke of remembering the hard things and not being able to spontaneously conjure up the good memories. **“Everywhere I go I think – that is where I had to stop and suction him, that is where I had to call the ambulance.....I just remember the end”**. They did some renovations to the house in 2021 to make it easier for her son but now it is too hard, too many reminders of what is not there, and she is thinking about moving when her daughter finishes school.

Other parents also spoke of the significance of their child’s space in the house. They have not yet changed anything about their child’s room. One parent spends a lot of time in the room talking to her child. Another parent told us that the room her child was in before she died does not feel like her real room as they had swapped her into the master bedroom in the last 12 months of her life. Only her things are in the bigger room, – **“her ashes are in a teddy bear on the bed, her birthday cards from January are still there and the balloons from her celebration are still there, deflated on the floor”**. She has a big 3D sign of her name that has never been put up and butterflies still up in her old room. Her mother wants to move her things back in to the room that was hers for most of her life,. Now everyone in the household has agreed

that they are comfortable with the rearrangement, her mother now has to find the energy – physical and emotional, to make the move. Another parent spoke of how she struggles when her grandchildren go into her son’s room to play with his toys. Her older son said to her – **“It will always be his room. The grandchildren will never sleep in there, not because he passed in there, but because it is his room”**. They also have a candle burning in the child’s room constantly – and electronic candle when there is no one home and a real candle when they are home. She told us her daughter turns off the electronic candle and lights the real candle when she comes home from school.

Parents spoke of how they keep their child’s memory close. Two parents have the face of their child tattooed on their skin, close to their heart. One parent commented that she there are lots of tattoos she is still to get. She particularly talked about her child’s hands – **“I miss his hands, his scars.... I know his hands intimately. They are not like any other hands; you will never see hands like his anywhere else”**. She told us that he had beautiful hands, but they were twisted and gnarled and unique. She intends to have his hands tattooed on her thighs so she can feel like she is holding them whenever she puts her hands on them. She would also like to get a sculpture of him . Another parent told us that **“Our child is a constant in our house”**. She told us she is always wondering what he would be like now – **“What would he be like now? He would have been 8. I talk to my husband about**

**who this little person would be”**. Parents spoke of the passage of time and how difficult it is to imagine that this living without the child will go on and on. One parent said: **“Every day feels like an eternity, but you look back and can’t believe how quickly time has passed”**. Another commented – **“How has it been so long...I don’t want to be 10 years without him. I don’t want to wake up one morning and realise he would have been 30”**. And another commented:

**“There is still a lot of life to live without them”**.

There was discussion in the group about how different life is without their child and how unfamiliar it feels. One

mother went to a concert – the tickets had been bought before her daughter died and it felt somewhat wrong to be going out when her daughter was dead. Parents also talked about how strange it felt to be able to just do ordinary things, like going to the supermarket spontaneously. For the parents who had been providing 24-hour care for their child this is a new and still strange experience. All parents talked about how foreign it felt not to have to consult their diaries every time someone asked them to do anything. Their diaries were full of appointments for their child – medical appointments, therapy appointments, inpatient admissions, and many other things. Now there is no need to have such a diary and it is another reminder of the loss. As one parent said – **“I was always organising things for her, checking the diary, keeping a record of everything she did every day.**



**What do I do with my time now?”** Another mother told us that it feels strange that she and her husband can now go to the football together when one had always had to care for their child previously. One parent said **“We sold the car.... I’m glad it’s gone. I’m driving a little car now and it feels so strange. I am used to being up high when I’m driving”**. Priorities change when you are grieving the death of your child. Things that were important, are no longer. One parent told us that she can’t keep her house clean any more. When their daughter was alive the house was spotless **“We ran the house like a hospital”**. Now it all seems too hard or pointless. She said she was trying to keep busy, hoping that would help but it isn’t helping. A parent told us how going out was very difficult for her and she had only recently gone into a supermarket for the first time since her child died. She told us about the effort needed to go out – **“It takes a surge of energy trying to do anything. It takes a lot of effort to do things even 7 years on”**. She told us how she had attended her nephew’s birthday party, and someone had commented to her sister how she looked so happy. She said, **“You can’t look sad all the time, but if you look happy people think you are over it”**. She told us that as soon as she had left the party and was on her way home, she burst into tears. She told us she has three safe places – her home, the cemetery, and a particular picture theatre she used to go to a lot when she was pregnant. Any other places require putting on a front.

Many parents do things to create a legacy for their child, to commemorate their child’s life or to create a positive from this awful experience. One family participate in the ‘Run (walk) for the Kids. 21 family and friends were going to be part of the team for the walk which was to take place the weekend after the group. She said: **“It feels like he is there when we are all together”**. She told us it would be a difficult weekend for her with the walk for the Kids, the beginning of the footy season and her birthday. Another parent told us that they had donated their child’s commu-

nication device to another child with the same condition. The mother had visited the family to give them the device and met the three-year-old child. As this is a degenerative condition this child was not as disabled as their daughter had been by the time she reached the end stages of her life. She told us, when the child’s mother asked her what it was like for her **“I couldn’t really tell her. I couldn’t tell her just how brutal it is. You don’t need to know that when your child is just three”**.

We heard about some other wonderful things that parents had done with their child. One parent had been upset about the way the children at her daughter’s school seemed to be almost afraid of her son. To address this, she got permission to talk to the class about her son. She showed how she feeds him, talked about him and the equipment he has and why he is like he is. After that the children would come up to her in the school grounds and talk to her son, ask questions and comment on the wheelchair. She had special hubcaps on his wheels and Geelong footy club paraphernalia and other fun things. **“I miss kids coming up to talk to him. I miss being his mum. Every second of every day is hard”**.

As we discussed how the different parents in the group are living their life after loss, a parent said, **“You can have good days when you have a real gut laugh, and I have those times, but then the silence hurts”**. She said: **“Do what you need to do. You do not want to have any regrets about how you have grieved and what you have done to honour your child”**.

As time ran out there was still so much more that could have been said. The group was very aware that death and grief are not easy topics of conversation in our Australian culture. Being in a group like this enables them to talk about their grief and how they are managing to live their lives after the loss of their child. We hope their stories and reflections resonate with you also.



*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 20th April 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:

**“Grief and Hope”**

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,  
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**Social Work Department, RCH**



