

**FAMILY BEREAVEMENT SUPPORT
PROGRAMME**
Social Work Department
NEWSLETTER OCTOBER 2018



Welcome to the October 2018 newsletter of the Family Bereavement Support Programme. We hope that in reading the newsletters and being a part of the groups you will find connection with other parents, support and encouragement to help sustain you as you grieve for your child.

“What do you think professionals should know about caring for the dying child and family.”

The group who gathered for the October bereavement group was, as always a mixture of parents of children who had lived only a short time and some who had lived into their teenage years. Some had been bereaved months only and some years. All generously shared their stories of the care they and their child had received in the course of their illness (if they had been ill) and particularly in the final days and hours of their child's lives.

We first heard of the frustration of being asked to repeat your story many, many times: **“I found it extremely frustrating to have to go through my story multiple times to every professional every time I brought my child to emergency. It was exhausting. I wanted to say ‘just read the file’ and I just wanted to be with my child”.**

Parents talked about the importance of the relationship between the staff and the child – the knowledge that staff saw their child as a real person and not just a patient. One parent told us – **“I saw the more human side of the doctor when I knew things were going bad. I am still in contact with her many years later. I have been told she still has a photo of my child”.** Another parent told us that police and professionals still call them and that some nurses attended their child's funeral.

The relationship between the staff and the family was also of critical importance. When this relationship wasn't there parents remember this and how difficult it was – **“His bedside manner was terrible – he had a lack of personal skills”.** Another parent told us of the importance of the relationship she

developed with the social worker and the nurse in the few days her child was in hospital before they withdrew life support – **“I loved my social worker and had the same nurse for what felt like the whole time. I always want to send her a letter. The head of ICU was with us the whole time.....Everyone was so caring and loving. Everyone was fighting back tears”**.

It is very important for staff to acknowledge the relationship between the parents and their child and find opportunities to strengthen this relationship in a time and place when parents can feel they have no control at all. We heard a beautiful story of the consideration and thoughtfulness of staff – **“It was my birthday when he was in intensive care and they made a birthday card with his hand and foot prints in it and they gave me a cuddle with him”**. Parents were very appreciative of the effort nurses went to to give them opportunities to do things with the child when they had lines, tubes, wires and machines attached. The significance of cuddles, bathing the child, even a bed bath, changing the nappy, applying lip balm – all these things helped parents to feel they could still be a parent even when their child was so dependent on machines and medications. **“I remember they would take him to the bath for me or organise a bed bath with me and it took so much effort I used to keep saying ‘sorry, sorry, sorry’”**.

Another parent told us how the nurse had asked her if she wanted to change her baby’s nappy: **“I’d never been able to change his nappy. I was so glad I was given the option”**. In contrast another parent was upset that after her child had died a nurse changed his nappy while she was in the bathroom. She said: **“I was not angry with her, but I would have liked to change his last nappy”**. Having some control when it feels like you have none is significant to parents – **“I remember looking at all the lines and all the drugs going into him and I thought ‘he has barely had Panadol before’. I felt like I had no control”**. Things that may seem small to staff can be so meaningful to parents. When there could be consistency of staff this was greatly appreciated by families. One parent told us that when her child was dying and they moved from intensive care to the ward 2 of the intensive care nurses came with them and nursed him in the ward. She knew this was exceptional and was so appreciative of this demonstration of how much her child meant to the nurses

It is very important to feel that your child is remembered and talked about after they have gone a parent told us how much it means to her that her child is still remembered and talked about by the medical team who cared for him and tried so hard to find out what was wrong with him. She has been told that her child is still talked about when there are discussions or conferences about

the condition he had - **"Having this contact is keeping him alive"**. It is also reassuring that the knowledge that was gained in diagnosing her child may prevent other parents from the nightmare of not knowing what is wrong with their child, something that used to **"drive me mad"**.

Another theme that was very strong with the parents in the group was the importance of people being honest with them about what was happening with their child. No matter how hard it was to hear, it was always better to be told the truth. We had stories of compassionate honesty and of times when staff were not as honest with parents. One parent told us her story and explained the importance of not only being honest but of talking in a way traumatised and shocked parents could absorb. **"I was told on arrival to prepare myself ...They talked at our level. They knew we were in shock. They told me every time something was happening and every change. The doctor was amazing, he talked slowly and told us something then paused so we could absorb it then talked, then paused. He was so supportive of us"**. For some other parents their experiences were different. One parent told us what happened in her child's last hours when they were in the hospital with him and both parents were asleep in the room with him in the early hours of the morning. **"I was asleep beside**

him when I half woke up and heard his breathing had changed. The nurse was there and I asked 'Is he dying?' and she replied 'I can't tell you that', but I wish she had said yes or gotten a doctor if she didn't know. I would have liked to know what was happening. I knew what was happening but I wish someone had the courage to tell me the words....I would have liked someone to just say 'yes'... What if I had slept through that? Imagine I didn't wake up - I wouldn't have had the last 21/2 hours". This parent said she had been told on other occasions in a crisis that her child was going to die and she needed to come and be with him and say goodbye, but this time, when he actually did die, no one was willing to say what was happening. Parents commented on how much they appreciated the palliative care service and that they were comfortable to talk about what was truly happening, but they are in and out and not there all the time. A parent said **"I feel there is missing training"**.

Another parent also told us a story of not being told the truth about the seriousness of her child's situation. She is herself a health professional and she knew how to read a MRI scan. She told us that when they were taken into a room and shown her son's brain MRI she knew immediately that the damage was catastrophic, **"the doctor wasn't aware I could read the scan. They kept talking about neural**

-plasticity and things I knew weren't possible. After the meeting my husband and mother thought it wasn't as bad as I thought and I had to explain to them that it was. The next day we got the head of neurology called in and he told us I was right". It was very hard for this parent to shatter the false hopes of her husband and mother, hopes they had because the doctors had not been honest with them.

Parents went on to talk about the importance of having those last moments with their child and of having someone who could guide them through. Parents all had different experiences of this time, some better than others. **"At the moment of death no-one was helpful. Palliative care seemed to know this information but they were not there at the death. I needed reassurance about what was happening".** Another parent told us - **"Children want their mum's and dad's 'til the end. I'd run to the toilet and back to spend every moment with my child. I didn't want to drink because it would make me need to go to the toilet.....As a mum I knew it wasn't good and I couldn't leave.....I have many regrets but I had to be there at the very end".** Parents spoke of the importance of having some time with their child both before and after they had died. A parent said **"I can't imagine not having those last moments. I filmed every second. I re-watch him pass**

away to see him alive, see every tiny detail". One family who had lots of family members arrive after the child passed away was asked if they would like to move to the bereavement suite. Looking back she wishes they could have spent more time in the hospital room which had been their home for so long. It was particularly hard when they were told they had to clean out the room as the cleaners needed to get in and clean. **"All his things, his toys and everything were just shoved into plastic bags..... I needed time, I wanted more quiet moments with no one around. I just wanted to sit in the room. I'd like to sleep there one night. I watched so many sunrises and sunsets with him from the window in that room.....every second was so precious".** This was a sentiment echoed by many parents - **"When you're told 'he's going to die', if you could take back those last moments you would take that forever, touch their hair, kiss them forever".** One parent told us that she felt she was given the time she needed: **"I didn't feel rushed at leaving. I was ready to go home. Staff gave us time on the ward. I treasure the time of lying with him on the bed".** Others found it very difficult to leave the hospital without their child. One couple told us they spent hours sitting in the car park unable to start the drive home.

For some families it was important

to have more time with their child and they chose to take them home. Not all parents felt this was something they would have wanted to do. For one their child had never been home, his home was the hospital and there was much grief when the old hospital was pulled down – the only place her child had lived. For the parents who did take their child home this was very significant and helped with their grief. One parent had to have her child embalmed in order to have him at home while another was able to have their child home in a special cooled bag, like a sleeping bag that the funeral home was able to provide. Both parents felt they had to ignore the opinions of those who felt this was an inappropriate thing to do in order to do what they knew was right for them. **“We brought him home for his birthday.....We were able to have the funeral at home. We put him on the couch and watched his favourite TV shows.....We had photos taken of him at home. He slept in my bed with me as he always did. We had someone come and do plaster casts of his hands and feet. I had no time, but these things gave me a little bit of time. No matter how much time you get it is never enough”**. This parent really emphasised the importance of slowing things down. They were being told to organise a funeral before they had even really absorbed the fact that their child

had died. **“Time needs to slow down. There is no time, but you want to slow down”**.

The families who attended the group also talked about the value and importance of the mementoes that were created both by the hospital and by themselves. One parent said **“I was very thankful we could do some things like take him outside and take hand and foot prints. It was a blessing we were here and got these things. Families want these things down the track”**. A number of the parents knew of others whose child had not died at this hospital who were not offered mementoes. Some parents had plaster casts of their child's hands and feet made. It was a great comfort to be able to hold this cast which is just like holding the child's hand, and looking at the feet – **“They are his feet”**. There are many ways of creating mementoes, prints, finger or hand print jewellery, photos and many more things. Parents felt they needed guidance around not only what was available for mementoes, but also what other options they have available to them regarding the times both before and after the child's death. A parent told us: **“There are so many options if you are just told. We don't know, we have never done this before”**. Options like being able to take the child home, different types of funerals, timing of funerals and so forth. Some parents look back and wish they had been given more

information or had the courage and support to do what they felt they needed to do, regardless of the opinions of family, friends and community. One family donated a cuddle cot* so that other families can have the option of taking their child home to spend time with them. This is a great gift health professionals can give to parents – the gift of options and choice in a time when so much choice has been taken away.

Some parents also talked about the importance of support and compassion from those outside the hospital. One couple told us **“We are carried and loved by the community”**. Another parent told us how important her spirituality is for her in her grief and in her understanding of what happened to her son and why. She shared with the group how much this exploration of Buddhism has meant to her. She said: **“The professionals were very nice, but they can’t help with spiritual problems. My son’s problem was a spiritual problem”**.

We should never forget the importance of place for families and the significance of the hospital as a place where their child may have spent all of their lives or a significant portion of their lives. Even if the time spent at the hospital was actually very brief, that time was so intense and full of emotion that the hospital may then have a very special meaning in the life of the child. Some parents

whose child had been in the old hospital spoke of their grief when the hospital was pulled down and the fact that their other children would never be in the place their sibling had been. Others spoke of wanting to visit their child’s room in the hospital and even of wanting to spend one more night there.

As we were finishing up the group one parent wanted to emphasise the importance of slowing things down: **“Rushing absolutely affects your grief – I needed to do things my way. I needed the time with him. I worry that others feel they have to do things out of ‘that is how it is done’**. It is so important for health professionals to listen to parents and to offer options and guidance in a time and place where very few parents have been before or would ever want to go again.

Thank you so much to the parents who shared their stories and their wisdom in the group.

*A cuddle cot is a baby bassinette with a cooled mattress run by a little motor to keep the body cool.



Straight from the Heart



WHEN THE HEART

*When the heart
Is cut or cracked or broken,
Do not clutch it;
Let the wound lie open.*

*Let the wind
From the good old sea blow in
To bathe the wound with salt,
And let it sting.*

*Let a stray dog lick it,
Let a bird lean in the hole and sing
A simple song like a tiny bell,
And let it ring.*



Our letter box is Waiting!



Contributions such as responses and reflections on the groups' themes, poems, letters, songs, 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

****If you would like to receive
the newsletter by email
please send us your email
details to the provided
email address.****

The next meeting of the
Family Bereavement Support Evening Group will be held on:

**Thursday 15th November 2018
7:30 pm – 9:00 pm
The RCH Foundation Board Room
Level 2, 48 Flemington Road
Parkville, VIC 3052**

Please join us to discuss the topic:

“Grief is like...Finding words to describe grief”

Please join us in November

The newsletter is always a team effort.

Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter and to Jennifer Burn for scribing parents' statements.

Also to Carlee Maggs from Holmesglen TAFE and Administration team for mailing assistance & to Marina Puljic for ensuring the newsletter is typed, formatted, collated and distributed to interested people.

