

**FAMILY BEREAVEMENT SUPPORT
PROGRAMME**
Social Work Department
NEWSLETTER OCTOBER 2017



Welcome to the September 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 can we learn from differing cultural expressions of grief, death and mourning”

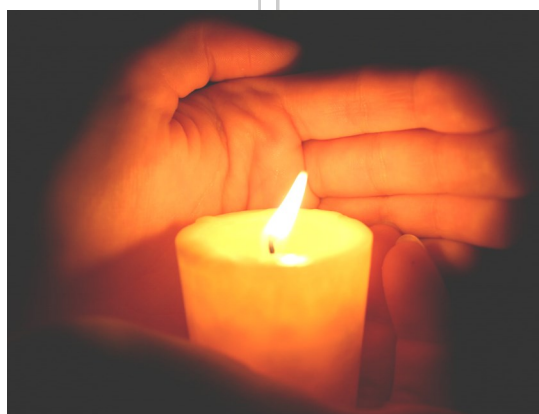
With the end of October/beginning of November approaching when different cultures and traditions typically have a time to remember those who are no longer here or to acknowledge death in some way – All Saints Day and All Souls Day, Halloween, The Day of the Dead, we decided it was an appropriate time to consider different cultural expressions of grief and different ways of coping with and acknowledging death. Those in the group agreed that in mainstream, modern Australian culture we do not have any clear rituals or guides to provide us with a ‘roadmap’ for grief following the loss of someone we are close to and certainly not to assist with the death of a child. We wanted to explore if there is anything we can learn from other cultures and the rituals that people create in the absence of a culturally determined ritual or series of rituals.

As in most groups we

had a mixture of people – mothers and fathers, people new to the group and others more familiar with the group. Some were recently bereaved and had not yet experienced many anniversaries and others had more experience with coping with the relentless passage of time. We were introduced to children whose lives had been very brief and others who had lived for varying periods.

All those present in the group said they did not come from a culture or faith group that had clear, predetermined rituals regarding what to do when a death occurs, funerals, or grieving. Some felt that this could be a good thing as they were then free to create their own rituals.

One parent reflected – **“You can create your own culture including whatever you can adapt and embrace from other cultures”**. Some people in the group had family members who had different cultural beliefs from themselves and had



different ideas about what happened after death. Initially this could be a source of frustration and even anger, but after a while, a parent told us, she came to reflect on and appreciate these different perspectives without feeling she had to adopt any of them. She said: **"Culturally we have made our own way along"**.

People in the group spoke about what they did in the days immediately following their child's passing and how they now felt about their decisions. One couple spoke of their experience with taking their child home from the hospital. They were asked after he had died what they wanted to do next. They really had no idea but were very clear that they wanted to take him home with them. **"After my son died I didn't have a guide. If I speak of him proudly, how we got him embalmed and took him home, it may be strange to some people. No one had anything bad to say about our decision to have him at home, but we were given incorrect information and he was taken away earlier than we wanted"**. Without a clear guide, people struggled with knowing what their options were regarding their child in the immediate time following their death and what the implications and details of a particular course of action would be. Some parents had regrets about their decisions during this most distressing and difficult time while others were confident that they had been able to do what was right for them and their family at the time. One parent in the group commented **"It's great that you don't regret your decision to take him home. I felt if I brought my child home I would never have been able to give her back"**.

Even when you know what you want to do and are supported to do this, a lack of comprehensive information can still lead to regrets. The mother who did bring her child home told us that she was asked at

the hospital if she wanted to give her child a bath. She said she did not want to do this at the hospital, as she wanted to give him his final bath at home. She was therefore very distressed to find that when the funeral director brought him home to them after he had been embalmed, his legs were wrapped in cellophane and they were unable to bathe him. No one had told her that this would happen. **"My child's favourite thing to do was have a bath and I feel horrible as he loved baths. That really broke me"**. Some other people in the group said that they also would have liked to bring their child home but either did not realise that this was an option or were unable to do this for other reasons - **"Sometimes the decision is taken away. My daughter had to go to the coroner and was there for 6 days. Those immediate decisions were taken away"**. Another parent told us - **"We took our child for a walk in a pram after he died"**.

It is not only general cultural beliefs that can influence people but also beliefs peculiar to our own family. A parent spoke of how her upbringing had influenced her at the time her daughter died. Her mother was very clear that it was not a positive thing to view a body due to a bad experience she had in her life and this belief had been transmitted to her children and influenced this parent at the time of her own child's death - **"I grew up with not being around dead people and I regret not spending more time after my child died"**. In the absence of clear rules and in such unique circumstances one parent said **"At those moments you have to go with your gut"**. In our community today it is not common practice to have a body at home but in many places this is exactly what is expected and it would be considered very strange to have the body of your relative at a funeral parlour. In some cultures the family and even the community gathers to take part in a vigil with the body of the person in the

room. In such circumstances the person is not seen as a body but as the person they have been and this time is a time to show respect and to farewell.

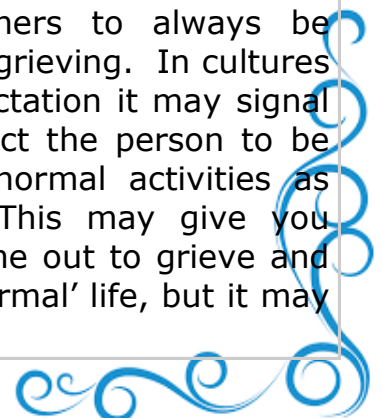
The most important thing for parents was that they did not have regrets. It is, however easy to look back and feel you would have liked to do things differently but at the time there is so much emotion and confusion that it is not always easy to think clearly, especially when you may not know what all your options are. A father whose baby died suddenly told us that his wife is Japanese. It was only when they returned to Japan for her mother's funeral that he realised that there are rituals associated with death and funerals that are not generally practiced in Australia. He wondered if there were rituals his wife would have liked to have when their baby died. He said **"thinking about culture, I wonder how it was for my wife"**. As a number of people said, we often create our own rituals, using what feels right at the time.

As we continued to talk the issue of cremation or burial and what to do with the ashes when you do cremate was raised. Some people had experienced pressure to make a decision about what to do with their child's ashes before they felt they were ready for this. One parent told us that her child was a young adolescent and was aware that he would die from his cancer. He asked to be with the family. Another parent has her child's ashes in a special urn in the garden. They are moving house and will bring her with them – **"Where we go, our child goes"**. One parent told us that they had decided to bury their child as at the time she could not contemplate her child's body being cremated, particularly after all the surgeries his little body had been through in his life time. She now feels that one day she will want to exhume him and have him cremated so he can be in the house with them. She is not yet ready for

this and knows it will be quite a process – at least 10 weeks, but she knows this is an option when the time is right. Another parent who has done some work with a funeral director told us that people ask to have their relatives exhumed more often than most people think. As we discussed the attitudes of others to the decisions grieving parents make someone said – **"There is no book to say what's right or wrong"**. In the absence of a clear instruction book parents can doubt their own decisions. A member of the group said **"I remember thinking, am I doing the right thing, but now I think I did it the right way"**.

A number of cultures have some way of showing others that an individual is grieving. This is most commonly in the form of wearing black or dull clothing for a prescribed period after the death of someone close to you. While those in the group thought there could be some advantages to having a way of showing others that you are grieving, most did not think the wearing of black was appropriate. **"To wear dark colours goes against everything about her. She was colourful and at her funeral colour was everywhere. I couldn't wear dark colours"**. Other parents also commented on colour at their child's funeral.

There was a feeling, however that if other people can see that you are grieving that may change their expectations of you. A parent said **"I wonder if the idea of seeing a signal of grief will trigger other people to be aware?"** There were some mixed feelings as to whether everyone wanted others to always be aware that they were grieving. In cultures where this is an expectation it may signal to others not to expect the person to be as fully involved in normal activities as they were before. This may give you permission to take time out to grieve and to slowly return to 'normal' life, but it may



also prescribe the time this should take and what is acceptable. Not everyone may be happy with this.

A parent pointed out that black armbands sometimes work as a sign that someone significant has died. This is particularly evident in some sports teams. It seems to be something that men do, rather than women. One couple put black tape around a post outside their home to acknowledge the loss of their child.

There was also discussion about different things people do or wear to remember their child. Tattoos are often a way of remembering and acknowledging a child. A mother told us that a number of family members, including cousins had a tattoo in memory of her child. This was not something that was discussed or planned. She said **"It is a sign of solidarity... It's great as it is permanently there"**. It is also their way of acknowledging that she lived and was significant to them and will not be forgotten. One grandfather got his first tattoo at 60 years of age as he wanted to have the child with him. Tattoos are a powerful acknowledgement and symbol as they are on your body and will be forever part of you.

Other parents talked about jewellery they were given or bought themselves to remember the child and keep them close. A piece of jewellery can be a very personal way of keeping your child's memory close – **"I found when I went back to work, I had necklaces to remember him but no one else knows what it means"**. In other situations some people may know



the significance of the necklace – **"I wear the necklace out and when I thought of him I was playing with the necklace. I wear it to family functions and our family know"**.

One parent told us the members of her playgroup gave her a special necklace when her child died with a circle symbolising her child. She has since added another circle for her younger child. This is the only necklace she ever wears and cannot ever envisage a time when she would wear a different necklace. She told us of her distress when she thought she had lost it once and her relief when it was found. Another parent told us how very important it was to her that she had been able to provide breast milk for her child throughout his life, even when he was unable to breastfeed. Her sister took some of her stored breast milk and was able to have it made into a ring for her. She said people react differently when they find out that her ring contains breast milk. Another parent has a lock of her child's hair in a locket she wears. She said **"I have a lock of hair in a locket and I have asked for no other jewellery. I can't not wear the necklace. It is my tattoo as it is permanent"**.

Some cultures have specific rituals to mark anniversaries, particularly a first anniversary. One of these rituals involves people gathering at the grave to unveil the tombstone. Sometimes there are particular church services to mark an anniversary. In one culture people gather at the grave and remove their dull clothes they have been wearing for a year, to reveal brighter clothes underneath. Although these rituals mark the significance of the passing of a year, it does not mean that the community expects that the family should no longer grieve. Most communities are aware that grief does not end at a particular date. Unfortunately many people in the group had experienced comments by others after the first year suggesting that their time of grieving should now be over. A parent shared her experience of this – **"After one year people say you need to move on"**. Another parent said you can feel guilty when you 'move on'.

A couple in the group had not yet experienced the first anniversary and were seeking guidance as to how they could mark this day. They were finding it particularly hard to think of an appropriate ritual as their child had never been out of the hospital. **"I want to start a tradition for her anniversary. Our child spent all her time in hospital and I'm looking for suggestions"**. Others in the group shared the rituals they had developed. It was interesting to hear that nearly everyone saw this day as a special time for those people closest to them – partner and children and sometimes grandparents. One parent told us how disappointed she was when she had invited people she believed were significant in the life of her family and her child to the cemetery to release balloons on the first anniversary of her child's death. She felt that many of them could not wait to get away and stayed only as long as they felt they had to in order to be polite. She said she would not involve those people in anniversaries in the future.

Parents generously shared with us some of the rituals they had developed to mark their child's anniversary. One parent told us **"We get away, just us, and then we do something as a family. Ronald MacDonald House was part of our routine so the children have a soft serve"**. Another parent said **"We do helium balloons and call it angel day"**. Some parents go to the beach, others try to think where their child may have liked to go, although this may be influenced by the opinions of the other children. The hospital has often been very significant in the child's life and this may form part of the ritual – **"Our child couldn't leave the ward for long and the day before his anniversary we came to RCH to have a coffee"**. If the anniversary falls on or close to a day

that is significant such as Mother's day, Christmas etc. there is another layer of complexity associated with the expectations of others. A parent whose child's



anniversary fell on Mother's Day told us **"I felt Mother's Day overshadowed her death anniversary and I had to share her day with everyone else"**. Having experienced this once, she feels more prepared for the next time this happens. A number of parents commented that the lead up to the day, particularly the first one is often more stressful than the day itself – **"I felt very anxious for the 1st anniversary, but it felt okay on the day"**. One of the parents told us that in some ways the second anniversary is harder than the first as people have moved on but also as it is a reminder of the passage of time and the fact that the child will never come back. In a similar way each New Year is the start of another year your child will not be part of. While everyone agreed that Christmas is hard, some felt that New Year was even harder.

It is not only the anniversary of the day the child died that is significant. Birthdays are also difficult and other days can also carry a particular significance for particular families. Some parents told us how they mark birthdays. This is often not such a private and intimate ritual as the anniversary of the death – **"I light a candle for her birthday and anniversary. I used to look at her photos and videos everyday but now I do on her anniversary"**. Another parent told us that she always sings her Happy Birthday and another that they always have cake for the birthday.

There are many other ways parents remember and honour their children. A couple of parents have instituted school awards in their child's name. **"He really enjoyed school and the motto was**

'never give up' and hence the award we sponsor".

So many people in the group had experienced a lack of understanding about grief not only from family, friends and other people they encountered but also from health professionals that they wondered what they could do to help to educate people. Someone said ***"We don't have a language about grief"***. We thought that in some communities and cultures death is much more open and less hidden and feared. In Mexico they celebrate the "Day of The Dead" and the whole community joins in remembering the lives of their loved ones. One of the parents in the group knew someone who had gone to Mexico specifically to be part of these celebrations. She said it was a wonderful experience and she wished the Australian attitude was more open to such celebrations. Others told us about family who feared their children would be traumatised by attending a funeral or by being involved in activities to celebrate the life of a deceased child. Such experiences reflect a community that no longer sees death as a normal part of life or allows people time and space to grieve. Sometimes when you develop your own traditions other may adopt these also. One parent told us that she always cooks something to remind her of her grandparent on the anniversary of her death. She notices that now other members of her family do this also.

Two of the parents in the group have



been involved in providing grief education to professionals through Compassionate Friends. They were both disappointed to find that most of those who attended the education were people who worked with adults who were dying, not children. The group felt that the grief associated with the death of a child is not the same as the grief associated with the death of an adult, particularly an older adult.

As we reflected on the discussion that had taken place throughout the evening it was interesting to note some very consistent messages:

- It is important to develop your own culture and traditions around loss, remembering and celebrating your child's life. These rituals and traditions may develop and change over time. Do what feels right to you. You may draw on existing cultural traditions but you may adapt and change them to meet your own needs or you may develop something that is uniquely yours.
- Some times are too precious to be shared with those who will not respect this. It may be preferable to share these times and build traditions with those who are closest to you and your child and will appreciate the significance of these days.
- The more knowledge and information you have about what it possible, especially at the time your child passes away, the more likely it is that you will not have regrets about your decisions at that time.

We are very grateful for the contribution every person attending the group made to the discussion and to this newsletter. People generously shared rituals and traditions that they and their families have created. We hope those reading this newsletter have found something helpful here. Please feel free to share your own traditions and rituals with us via email or mail if you would like to add to this discussion.

Straight from the Heart



Thank you to Brennan mum's Bernadette
for her contribution

The blossom of the wattle is so beautiful to see;
I love its downy yellows and its olive greenery.
I love the way it wavers, and its nodding, perky leaves;
I love the way those leaves gather in big bunches of sheaves.

When I see a wattle tree, it makes me think of Brennan;
Why that's so, I do not know, I can't think of a reason.
I do not know he liked wattles, I don't know that at all;
But when I see a wattle, it's as if Bren made a call.

I feel he's sending love to me, to tell me that he's near;
That even though he's gone away, his spirit is still here.
That he'll be watching over us, whatever we may do;
And his love for all of us, is just still as staunch and true.

So when I see a wattle tree, I stop and breathe it in,
And think of Brennan's laughs and glee, his jokes and cheeky grin.
I admire those graceful blossoms, revel in their flow'ry smell,
And wish that ruddy cancer had just gone straight to hell.

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
address.****

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

**Thursday 16th November
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:

***“The dilemma of investing in life while remembering
and honouring your child”***

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 Tatiana Cabral for scribing parents' statements.
Also to the RCH Volunteers for mailing assistance & to Jenny Jelic for ensuring
the newsletter is typed, formatted, collated and distributed to interested people.*

Social Work Department, RCH

