

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER APRIL 2017



Welcome to the April 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.

“The experience of grief; Where am I and am I normal?”

We welcomed people to the April group. Some parents were attending for the first time and others were more familiar with the group. As usually happens in these groups parents had different stories and different experiences of their child's life and death as well as different periods they had been living with grief. All shared the life changing grief of having lost a child. One of the most wonderful things about this group is that everyone respects the opinions and experiences of others. We discovered tonight that different people respond to aspects of grief differently with no one way of behaving being more 'normal' or more



legitimate than another.

As the topic was about the experience of grief and what is 'normal', following introductions we began to explore some of the understandings of grief that have been developed by theorists over the years. One of the early writers about grief was Elizabeth Kubler-Ross who tried to understand grief by talking to people who were facing their own death. She developed a staged theory of grief and suggested that people move through 5 stages, the final stage of which is acceptance. The other stages are: denial/isolation, anger, bargaining, sadness and finally acceptance. This theory has also been applied to the grief people

experience after someone they care about has died. This theory is now very old and understandings of grief have changed, but people still refer to stages of grief and the need to move through these stages.

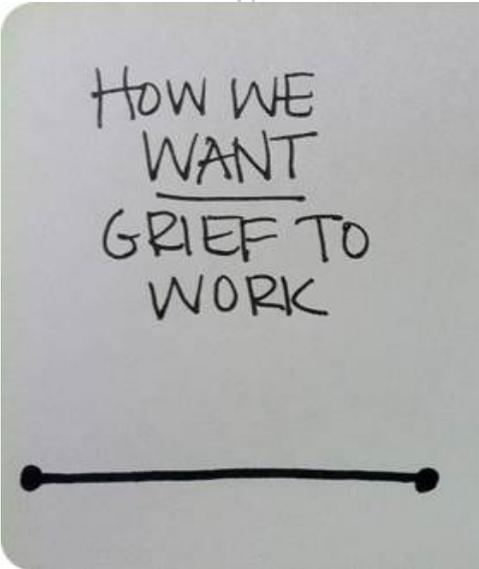
The group was asked their opinion of this theory in their own experience. One parent who had known her child would die at a young age said: **"when you know death is inevitable, you do go through stages, but when they do actually die you go through it all over again"**. There was also discussion about never wanting to get to a stage where you 'accept' that your child has died or will die. Some parents said this felt like it was forgetting your child and carrying on with life. They never want to forget their child – feeling the pain of the absence is part of the remembering. There were a number of comments about anger. One parent asked **"Is it normal to still be angry four years after her death?"** In general the group felt that there is nothing abnormal about this. It was evident that people respond to things differently, with some being more likely to feel angry than others and to feel angry at different things. This can be the case within couples, with each dealing with their grief in different ways. Some parents were angry with the world in general and with the

injustice of their child dying. For some their anger was more targeted – **"We focused our anger on the medical team we feel was responsible for her death. Four different medical opinions assessed the care was 'adequate'. There will be no coronial inquest and now I feel angry again. I feel like the system has failed her. I feel the anger will always be there for that medical team"**.

Another parent said: **"I'm just angry at life and my target is all the people who say stupid things to me – what do they know about what I'm going through? A stranger told me 'I know why this happened to you – God was trying to make you a better person'"**.

Another parent responded that she thinks people feel they need to say something instead of nothing but they do not understand that sometimes saying nothing is better. For these parents anger did not feel like a stage to be 'worked through' but a part of their daily life with grief.

We then went on to discuss other, more current understandings of grief. One theorist, Worden suggests that there are four tasks of mourning – to accept that the loss is real; working through the pain of grief; adapting to a new environment where the deceased is missing; finding a way to make an enduring connection with the deceased



person while moving on with life. Another theory suggests that grieving people move back and forth between being, on the one side focussed on their grief and their loss and, on the side being more focussed on restoration of life. The thinking is that people move back and forth and will initially be more on the loss-oriented side but will slowly spend more time on the restoration-oriented side. Grieving people oscillate between these states frequently and also need some time out from the intensity of their grief every now and again. Some diversions can take you away from the grief for a brief period.

The final understanding that was discussed was the acknowledgment of the importance of enduring bonds – finding a

way to keep your child present in your life and in the life of the family. A parent once said that your grief never diminishes – it stays the same size and you grow around it.

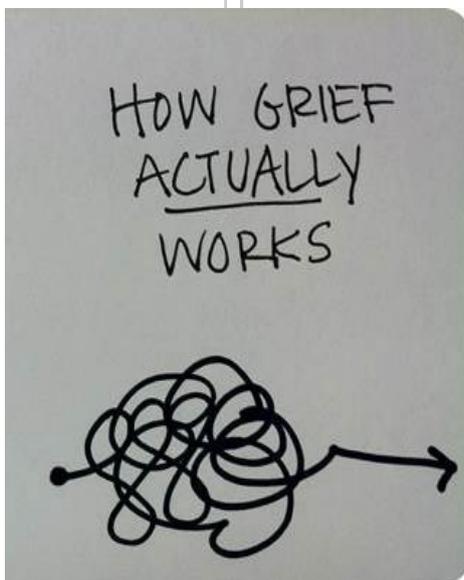
In reflecting on these different ways of understanding and describing grief one parent reflected that she thought that her family would prefer it if she did pass through stages **"so that I could end up back how I was"**. Some other parents agreed with this and said **"that person is gone and that version of me will never come back"**. Many things in life change us,

becoming a parent is one but becoming a bereaved parent has an even bigger life-changing impact. One parent said that the couple relationship also changes. First you have to adjust to being parents and then to not being parents of a living child. **"We had to adjust to becoming a couple, and reconnecting again after the loss of your child is enormous. Years later we became parents again and had to adjust again"**. Parents also need

to adjust to the changes in each other and their different needs and styles of grieving. One parent said – **"As a couple we are completely opposite in how we grieve"**.

The suggestion that grieving people need to accept the reality of the death sparked some interesting discussion.

One parent said: **"I can't get my head around the fact that we had a little girl and she is now not here – she died and she is not coming back, ever – I struggle with this every day"**. Another parent said: **"We had our child for such a short time that sometimes I question, did it really happen; did that really happen to me?"** While there is the difficulty of really believing that the child is no longer with you, there is also the reality that some things are forgotten – **"sometimes I try to remember what it was like to have both my children together – I hate**





it that I forget what it was like”.

People in the group talked about the expectations of others, the insensitive comments and the lack of understanding about their grief. As had been discussed earlier, the inappropriate comments of others invoke an angry response from some – ***“I just tell people to piss off”***, others have a different response – ***“Friends just want my grief to be over and done with because they feel uncomfortable around me”***. One parent reflected that sometimes it depends who it is who makes a comment as to how you feel about this comment. ***“A doctor who fought so hard to save her life said ‘someone else needed her’. I could only accept those words from her”***. Others said that they can accept some things from friends they cannot tolerate from family who they expect should know how to be more sensitive. Other comments people have made include ***“God will never give you more than you can handle”***, ***“God needed another angel in heaven”*** and ***“He would have wanted you to be happy”***. Parents found these comments and others like them insensitive and infuriating. When

children suffered before they died these comments seemed even more insensitive – ***“My daughter suffered for a whole year, so I can’t believe God just took her to be an angel. If he wanted her to be an angel why couldn’t she have died peacefully in her sleep?”***

Relationships with family and with friends change with some who you expected to be there for you disappearing out of your life but with others stepping up who you did not expect. ***“Some people can’t cope with the changes in the dynamic in the family, or they don’t know how to support you and be with you in your grief”***. One parent has found that, some years on most of her friends are now people who are also living with grief – ***“We only mix with people who have also experienced this grief – they understand”***. Another family are struggling to understand why all the people who came to support them when their child was dying are now nowhere to be seen – ***“I’ll never understand this – they wanted to be with our child but why aren’t they there for us now”***. Clearly this was very painful, when you think people will be there and they are not.

There were some experiences of people showing great understanding. One couple told us of how pleased they were when their child’s godparents ask to visit the cemetery with them. Not everyone feels comfortable visiting a

child's grave but for these godparents it was a way of acknowledging their ongoing connection to the child.

A number of the parents in the group had other children, some born before their child died and some with children born subsequently. The group reflected on the impact on parenting of their grief. One parent felt that her son had lost not only his sibling but also the parents he should have had. While they feel they are good parents they believe they are not as happy or relaxed as they would have been if their other child were still alive. **"You are dramatically different parents, over protective. We are broken and sad. It is so unfair for him. He lost the parents he should have had"**. Other parents in the group felt that their grief did not necessarily have only a negative impact on their parenting of their other children. **"I am excited about what our other child can do, given our first child was so disabled, but we don't do so much with him as we did with our other child"**. Another parent said: **"I feel we have been on edge for the whole life of our second child"**. Many expressed the feeling that there is a mixed bag for the other children with some aspects of parenting enhanced and other aspects damaged. **"I feel we loved our next child much more having lost our first one. I've chosen to stay home and care for him. We**

may be broken but we give him everything", and another comment: **"We don't take anything for granted and little achievements become enormous"**. As subsequent children pass the age their sibling was when they died this can be a time of very mixed feelings for parents. For one parent whose child lived for a number of weeks she said it was like they were **"holding our breath"** until the subsequent children each passed this age.

The group discussed the issue of showing their emotions in front of their children. Some said they had been told that they shouldn't cry in front of their children, but most felt that it is important to be authentic in front of children and that they their children do see them cry. It was agreed that children need to know that it is okay to express your feelings. Some parents said that they feel their children are more compassionate from being exposed to real feelings. One parent said **"It is important to tell the child the tears are because you are sad about the child that died and not because they have**



done anything wrong”.

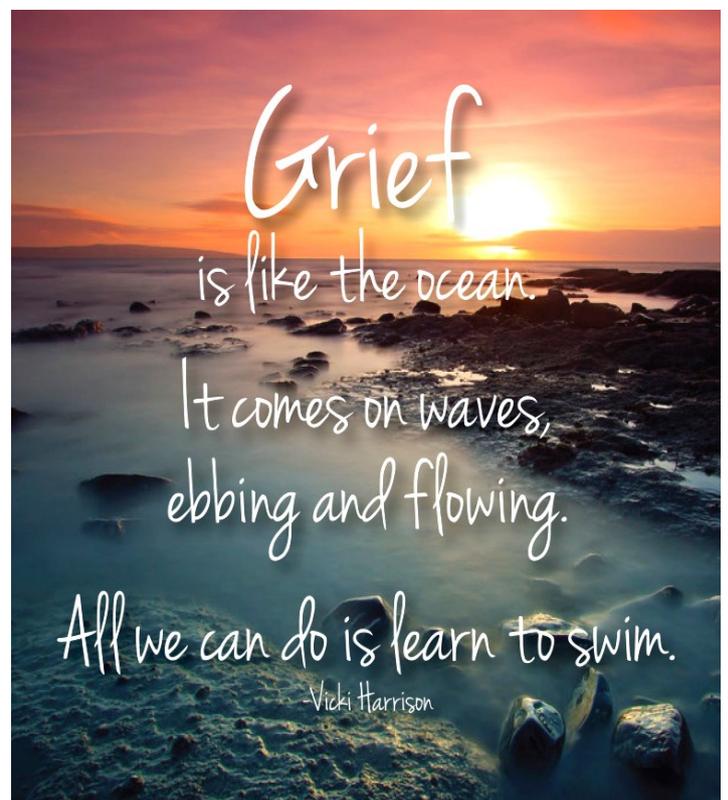
The death of a child feels much more enormous than the death of an adult and many parents in the group said this is their belief. One parent said **“Losing a child desensitises you to the death of adults and older people – nothing will hurt you more than losing a child”**. It was agreed that having a child die before the parent is not the natural order of things, and even the death of a relatively young adult is not as hard, nor is it the same as the death of a child. A number of parents spoke of their feelings on the death of an older person and said they simply could not feel the same intensity of grief, even when they were very close to the person who died.

How we are changed by grief became a theme through the course of the evening. There was no disagreement that grief changes you profoundly, **“Everything is measured in terms of before or after the death, as if we’ve had 2 lives”**. Another parent commented that **“We have much more depth and enrichment in life after what we’ve been through. It gives us a more profound perspective”**.

As we moved to the end of the evening we again visited the notion of grief and am I normal. One parent said that someone had once described grief to her like waves beating against the shore. At first you feel you are being constantly

knocked down by the waves and sometimes can barely keep your head above water, but slowly over time the waves ease off and become gentler and mostly just lap against your feet. But, this mother told us, 7 years on a wave can still come along and sweep her off her feet, leaving her fighting to get her head above the water again. This metaphor seemed like a good place to finish up the group for the evening. We hope those readers who are unable to attend the group could recognise some of your own experiences and feelings in this newsletter and that the newsletter has helped you to make a bit more sense of your grief. Remember, any written contributions, responses, comments or reflections by you to this newsletter will be gratefully received.

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## **My Lost Love My Lost Child**

I wonder what you're doing  
and how you're living life  
what new things did you learn today  
and how did you sleep last night

did you feel raindrops on your face  
or sunshine in your eye  
of all the questions left unknown  
the biggest one is why

why can't we be together  
why can't I watch you grow  
why can't I guide you through this world  
this I just don't know

but I promise we'll be together  
no matter how long it seems  
just know you're always in my heart  
and always in my dreams

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Source: <https://www.familyfriendpoems.com/poem/my-lost-child>

## *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 18th May  
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:

***“ When grief is all - encompassing is it possible to think of others?”***

Please join us in May

*The newsletter is always a team effort.  
Thank you to Helen Stewart for guiding the group discussion and for facilitating  
and to Flora Pearce for scribing parents' statements.  
Also to the RCH Volunteers & to Jenny Jelic for ensuring  
the newsletter is formatted and distributed to interested people.*

***Social Work Department, RCH***

