

# FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

## NEWSLETTER APRIL 2013



Welcome to the April family bereavement newsletter. On a very wintry evening a small group of parents gathered to share their stories and to hear Shirley Nash, a member of the pastoral care staff at the hospital lead a thought provoking discussion on faith and spirituality. Shirley used a beautiful book, *The Red Tree* by the Australian author and illustrator, Shaun Tan to guide the conversation. We hope this newsletter conveys some of the depth and breadth of the group.

## *The Red Tree – a story of Grief and Hope*

### Introduction

As people introduced themselves and their child they also commented on their feelings about their faith and spirituality, particularly in relation to the loss of their child. In the group we had people from different faith traditions and some who felt no connection to any particular faith group at all.

Some in the group were approaching the first anniversary of their child's death and one mother commented that although in some ways it seemed like a very long time it also felt like **"the quickest year of my life"**. She was finding it difficult to believe that it will be **"a year since we've heard her voice"**. Another parent also approaching the first anniversary talked about her ongoing

disbelief that her daughter could have died – **"We don't get sick, she had never been to hospital"**, and **"she skipped off to school that day and never came home"**. She also said it was so hard to understand why her daughter's great grandparents were still alive when they **"don't want to be here"** and her daughter was not.

There were many comments about faith/religion by parents as they shared their stories. As one parent said - **"she's got to be out there... there has to be something out there, the alternative is too hard to think about"**. The entire group agreed with this statement. A comment from another parent also resonated with the group - **"I always ask myself, will I meet him again"**? Such sentiments were universal, regardless of belief



tradition.

One parent who had been baptized a Catholic told us for her **“faith is important”**. She said that even though she believes in God, **“I have questioned God... I will have serious questions for Him when I get up there”**. She said it was important to her that she could picture her daughter in heaven with God. Her comment that **“none of us will ever have answers”** struck a chord with everyone present.

One parent told us that she is not religious. However she said that when her child was in ICU, the pastoral care person visited and - **“all the noise went away... we talked about (daughter). It helped me to let her go”**.

#### Last moments and regrets

As the conversation continued a number of parents talked about their last moments with their child and for some, regrets they had about this time. One parent who had spent some of her child's last day away from her expressed her deep regret about this but another parent said **“you will always have something to regret. You will regret all the time you did not spend with her. I was with my son, holding his hand all the time for his last days but I still regret the times I was not with him”**.

One parent said **“it is the most precious moment – to be with your child until their spirit is gone”**, and another felt privileged that **“my voice was the last she heard”**. Parents talked about the circle of life – you bring your child into the world and sometimes you also need to be there when they leave the world. Although you never want to do this, it is what you do as a parent. Those present in the group felt their children did not want to go - **“he wanted to stay”** and **“my child wanted**

to live”.



One family whose child had died suddenly and unexpectedly the day after Mother's Day spoke about the wonderful Mother's Day they had had – the last day of their child's life. They had been discussing the generations of the family and the experiences of ancestors who had faced the death of children. **“It was like we were meant to talk about it... It was the most beautiful day”**.

All 'special' days hold particular challenges for bereaved parents. As Mother's day is a celebration of motherhood, this day held distinct significance for a number of parents present and all were concerned about how they would get through the day. It is best to plan for these days. The expectations of others can be particularly difficult to deal with if they do not seem to have a good understanding of your needs. When a death coincides with a day like Mother's Day the grief of the anniversary can be compounded by the expectations of the day.

One of the families in the group had been asked if they wanted to donate their child's organs and had made the very difficult decision to do this. The decision was helped by the fact that when their daughter had seen a child on the television who needed an organ she said **“if I could help that little girl and give her mine I would”**. She **“was always a giving girl”**. While this helped with the decision it was still not an easy choice to make. One of the other parents said she was glad organ donation was not mentioned for her child as she felt **“she had been through enough. She had had so many operations; I couldn't have put her through anything else”**. Parents felt a great



responsibility making these final decisions on behalf of their child.

### Shirley

Following this discussion with many different positions about spirituality and faith being expressed, Shirley began to speak to the group about her understanding of spirituality and faith and introduced us to the ‘The Red Tree’, a beautiful book by Shaun Tan.

Shirley told the group that spirituality is about “*being present*” and is something deep within all of us. She said that although there are many people who do not identify with any organized religion or faith community, everyone has faith. Faith is something bigger than ourselves and simply getting through each day is an act of faith. Faith and spirituality are often about connections about relationships, family and love.

Shirley then read the “The Red Tree” to help the group to continue to explore the experience of grief.



*Sometimes the day begins with nothing to look forward to and things go from bad to worse. Darkness overcomes you.*

The group all identified with this sentiment – waking up in the morning with a feeling of darkness. One parent said “**early in the morning is the worst time. I am up first and I always go into her room and she is not there**”. Another parent said she had been happy for a moment one day and realized “**I only notice when I am happy, I don’t notice the sadness. I thought, ‘what an unhappy person you are’**”.

It was noted that there are many triggers which cause the darkness to overcome you. For one parent driving to the hospital is one

trigger as she had done this so often with her daughter and now she is not there. Many other triggers were discussed – music being one of the more powerful ones. Some triggers are predictable such as the school children walking home from school each day – “**they walk past our house and our daughter should be there**” -but others come out of the blue and catch you by surprise.

*Nobody understands. The world is a deaf machine,*

These lines from the book evoked a strong reaction from those in the group as all had experienced the feeling of not being understood so often. One parent said “**I thought I had to make people understand**” but clearly this was not possible for everyone. Shirley suggested that sometimes people can’t let themselves understand and it is too painful. Shirley went on to comment that misunderstanding may come from a need for others to protect themselves against emotional pain. However if we keep trying to educate others when inappropriate things are said or done it may be “**like water dripping on a rock and the person may begin to understand**”.

The expectations of other people are often hard to deal with, especially when they are family members. Others do not seem to understand that grief takes time, a lot of time. Statements such as “**she got her wings early**”, “**this only happens to strong people**”, “**God wanted another angel**” only bring anger and hurt, not the comfort they are perhaps meant to bring. As Nicole Kidman’s character said in ‘Rabbit Hole’ – “*if God wanted another angel He could have made Himself more*”.

A parent said that her faith tradition believes that what happens is “**what**



**God wants**” - it is the will of God. For her this brings some comfort. Several parents had been to mediums. After seeing a medium one parent believes her child told the medium that **“it’s all decided”**, that is, everything is preordained. This knowledge also provided some comfort. Another parent who had also visited a medium said **“your children are on loan to you”** and while this is a hard truth, one she did not want to believe, this also gave a degree of comfort.

People did have experiences of others understanding how they were feeling or what they needed at a particular time. Such moments of shared understanding could be very powerful and reassuring. A comment was made that coming to the group, there is an **“automatic and deep connection”** between the parents. One parent said **“we wouldn’t have to speak to understand each other”**.

without sense or reason.

The death of a child **“goes right against our world view”**. A number of those in the group reflected on their responses to the Good Friday Appeal and other news stories which show the good news stories of the children who have been cured by the Royal Children’s Hospital. **“The stories of the children and families that don’t make it through – you never hear them”**. For some parents this felt like a dismissal of their family and of their



child’s memory and did not reflect the reality of life. One parent said they have a team in Run For The Kids in memory of their child and they wear T Shirts to remember. As one parent pointed out, these events are to raise money and the public wants to hear good news stories and see appealing children if they are to be moved to donate.

Following this discussion a parent said **“it does go on, the hospital goes on for the parents”** in the form of the groups and the family bereavement program. In this way the hospital does continue to care and to remember.

There is often anger mixed in with grief – anger about the lack of sense or reason and the inability of others to understand. Shirley commented that anger is a normal emotion and that it can **“spur us on and energise us”**.

Sometimes you wait and wait and wait and wait and wait... but nothing ever happens.

The feeling that things will never change was something everyone identified with. **“It’s too hard, I don’t want to do this anymore”**.

Wonderful things are passing you by.

When Shirley asked what wonderful things could you be missing out on, one parent immediately replied: **“what joy have I missed from my little boy... all through no fault of his own”**. She also wondered **“how many times has he wondered where she is”**? Other parents also reflected on the impact of grief on their other child and on what they are missing out on both because of their parents’ grief and because of the absence of their sibling. **“Our son just turned 10, reaching that milestone without his sister. He was very quiet... you forget he’s feeling it too”**. He and his sister had shared a love of music.



When hearing a new song he said **“I just wanted to play her this song. I think she’d like it”**. Life moves on even if you don’t want it to.

Sometimes you just don’t know what you are supposed to be, or what you are supposed to do, or who you are meant to be, or where you are.

**“I wanted everyone to stop”**. This feeling of wanting the world to stop but finding you still have to get through each day can be quite disorienting and distressing – how can the world go on when your child has died?

A number of parents talked about how their identity as a mother has changed and been challenged - **“It’s scary, I can’t remember being a mum to two children”**, and **“I feel like I’m meant to be a mother to a sick child... I’m meant to be a mother”**. Although the group reassured those who no longer had a living child that **“you’re still a mum”**, a mother responded **“you have to look after someone, not just yourself”**. One mother said **“life changed when I became a mother and it will never be the same. You flick the switch onto being a mum and you can’t ever turn it off”**. How do you keep on being a mother when your only child has died?

There was also some discussion about relationships. A parent who had separated from the father of her child said that once their child became unwell, the issues between them didn’t matter. The only thing that mattered was that **“we were both parents”**. Although they are not together they have the shared experience of being parents to a beautiful child who struggled with her illness and died.

and the day seems to end the way it began. But suddenly there it is, right in front of you,

bright and vivid, quietly waiting, just as you imagined it would be: The Red Tree



Shirley asked the group if they had noticed anything hopeful, if they had hope in their lives. One parent responded **“I don’t have any hope yet. I feel angry. Why did mine go?... We’d finished our family... now we are unbalanced, a table with three legs”**. Other parents also felt there was no hope and even to have hope is disrespectful – **“it is disrespectful to do something else”**. There seemed to be a questioning of how you could have hope when there are **“so many things we have been robbed of”**.

Shirley pointed out that even to *“put one foot in front of the other”* is a hopeful act. She said hope can change and may be just a minute little thing. One parent responded to this by saying that from the time they first found out her daughter was ill the doctors talked about hope – **“first they said they hoped her lungs would get better as she got older, then they hoped she would eventually be able to get on without the feeding tube... I always stayed hopeful. Now there is no hope”**.

Some parents had hope that they would be able to have another child. This hope did not come without doubts and reservations, however. **“Will people think we’re trying to replace her”?** If this couple are successful they may have to pack up their daughter’s room to make room for a new child – this will be a difficult thing to do. Hope is mixed with grief. Much of their motivation to try to have another child is to give their remaining child a sibling.

Another mother hoping to have another child said **“I will teach him to love him like I do”**. She also said **“he was trying to live, not to die. I need to do the same. We have to continue”**.

A mother told us **“I feel comforted that I have an angel now. I’ve never had one”**.

Shirley suggested that symbols can help with grieving and with healing. She invited those present in the group to break off a sprig of rosemary from a plant she had brought to the group. She explained that in Gallipoli there were no flowers but there was rosemary growing in the area. Rosemary is for remembrance. To close the group we listened to a song by Eric Bogle which we have included in this newsletter. Shirley completed the group with a lovely blessing.

*May you go gently into the world  
Honouring the child you love  
Honouring your selves and the love you have offered  
May good memories bring some measure of comfort as you engage in your daily lives  
And may there be peace.*

We thank Shirley for her wisdom and compassion as she led the group and we thank all those who attended for sharing their wisdom and their experiences and allowing us to share that with other bereaved parents through this newsletter. May you all go well in the coming month as Mother’s Day is celebrated and life continues to move on.

Reference:  
Tan, S, 2001. *The Red Tree*. Australia, Marina Dalrea



## One Small Star by Eric Bogle

*When I need to feel you near me  
I stand in this quiet place  
Where the silver light of countless stars  
Falling on my face  
Though they all shine so brightly  
Somehow it comforts me to know  
That some that burn the brightest  
Died an eternity ago*

### Chorus

*But your light still shines  
It’s one small star to guide me  
And it helps me to hold back the dark  
Your light’s still shining in my heart*

*I’m learning how to live without you  
And I never thought I could  
And even how to smile again  
I never thought I would  
And I cherish your heart’s memories  
Cause they bring you back to life  
Some caress me gently  
And some cut me like a knife*

### Chorus

*Can your soul be out there some where  
Beyond the infinity of time  
I guess you’ve found some answers now  
I’ll have to wait for mine  
When my light joins with yours one day  
We’ll shine through time and space  
And one day fall on a distant age  
Upon some stranger’s face*

### Chorus

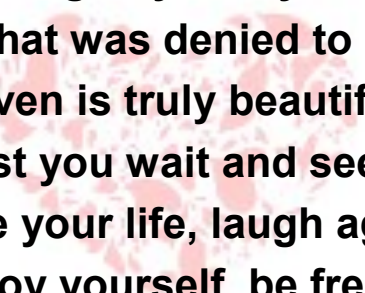
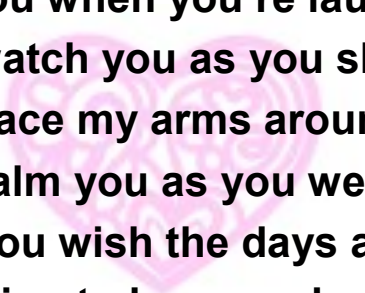
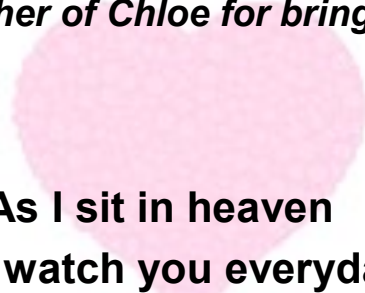


# *Straight from the Heart*



*We thank Kelly, mother of Chloe for bringing us this poem.*

**As I sit in heaven  
And watch you everyday  
I try to let you know with signs  
I never went away  
I hear you when you're laughing  
And watch you as you sleep  
I even place my arms around you  
To calm you as you weep  
I see you wish the days away  
Begging to have me home  
So I try to send you signs  
So you know you are not alone  
Don't feel guilty that you have  
Life that was denied to me  
Heaven is truly beautiful  
Just you wait and see  
So live your life, laugh again  
Enjoy yourself, be free  
Then I know with every breath you take  
You'll be taking one for me....**



## *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 are most welcome in the Newsletters. Share your thoughts, experiences and 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 May  
7:30 pm – 9:00 pm  
Ella Latham Meeting Room 2  
Ground Floor, West Building  
(Main Street)**

Our May group will be led by Kevin Carlin.  
Kevin works for Very Special Kids and formerly worked for SIDS and Kids.  
He has much experience working with bereaved parents and children  
as well as working with the families of children with a life threatening illness.  
The topic Kevin will focus on will be: **What about the other children in your life?**

Please join us in May

*The newsletter is always a team effort. Thank you to Shirley Nash for guiding the group discussion and to Helen Stewart & Tess McClellan for their assistance and scribing parents' statements .  
Also to the administration team & to Carly Blanche for ensuring the Newsletter is formatted and distributed to interested people.*

***Social Work Department, RCH***

