Family Bereavement Support Programme

Social Work Department

NEWSLETTER MARCH 2018

The Royal
Children's
Hospital
Melbourne

Welcome to the March 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.

"Reflections on decision making in the most difficult time of your life"

We welcomed a number of families to the group, some new to the group and others more familiar. We were also pleased to welcome an adult sibling who attended with her parents.

The topic for the evening was about making decisions. There are many decisions that families need to make when their child is unwell, when they are approaching the end of their life, and after the child has passed away. For many parents these decisions play on their minds and are questioned over and over along with the 'what ifs' and 'if onlys'. For some there has been a lasting impact on their ability to make any decisions. Tonight parents shared with us the decisions they had made and the decisions they wish they had made and how they now live with these memories.

Not every parent in the group had to make end of life decisions for their child. A parent whose child died suddenly at home told us: ***"There were no decisions – it was all taken out of our hands. I didn't even have to decide about organ transplant. I was glad we didn't have to make this decision. I would like to think I would have said yes, but I don't know. There are lots of things to consider"***. She did go on to say that there were many decisions to make after her child had passed away, including whether or not to agree to an autopsy. They made the decision to go ahead with an autopsy because ***"we had to know what had happened"***, however they felt they were not fully informed about what was involved. This mother said it was only when she read the report that she truly understood what an autopsy really meant. While this was distressing she still believes they made the right decision. This issue of having inadequate information and not feeling fully informed about a number of things was a theme that was repeated in the stories of many families.

Like many parents these parents questioned other decisions they had made – would they have made different decisions if they had known what was coming? Their little girl had hip surgery and was in a wheelchair for 6 weeks, only walking again about 10 days before she died. Her mother told us they probably would not have put her through this surgery had they known she had only a couple of months left to live but she also said ***"I turned this around and thought, at least I had 6 precious weeks with her. I slept with her for that time because we couldn't get her upstairs to her bedroom. I also had the 10 days in hospital. If she hadn't had the surgery she would have been at school and I wouldn't have had that time".*** Other parents also thought differently about decisions over time and could see the positives in the decisions that were made.

For parents whose child had a long illness, there were many decisions along the way, but also a feeling that many decisions were taken out of their hands and they had no control over what was happening to their child. A mother told us of her feeling of powerlessness when her newborn baby was admitted to the hospital ***"He couldn't breathe, he couldn't swallow, he was having chemo. I couldn't even decide how to feed him. All the decisions were taken out of my hands".*** Another parent whose child had a long, difficult illness echoed these feelings of helplessness because so many decisions were made by the hospital and were out of her hands. ***"In the hospital I was completely powerless. Every decision I did not have the power to make. Not having the power threw me – having to give my power away to the doctors and nurses – but they saved him many times before he passed away".*** There was an acknowledgement that although it felt terrible to not have control over what was happening to your child, there was no choice and it was the skill and expertise of the hospital staff that allowed the child to live for as long as they could.

A parent told us ***"the decision-making started when we were 20 weeks pregnant".*** Their child was diagnosed with a complex cardiac condition at that time and they were asked multiple times if they wished to end the pregnancy. ***"I felt even at the beginning when I was pregnant that there was no doubt – I wanted to have him, to give him life. He was such a miracle. I knew it was the right choice. We ended up telling them to stop asking".*** She went on to tell us that after the birth it felt like everything was out of their control but she has never doubted that to give her child life was the right decision. ***"I know they (the surgeries) were horrible for him, but he was so smiley and happy… I couldn't picture my life without him now".***

Many of the parents in the group had to make decisions to withdraw life support or not to have their child resuscitated when they deteriorated. These decisions were incredibly difficult and several of the parents present said they wondered if they fought hard enough for their child. One parent told us: ***"deciding to withdraw treatment for my child was a no-brainer… I have no doubt***

that withdrawing treatment was right… they told us he'd last 24 hours but he went on for 3-4 days. Then I started to wonder if we had given up too soon. I think you just question everything". Her child had come to hospital to get the chicken pox vaccine. His parents later questioned if he would have lived if he did not have the vaccine. When they asked this question they were told that there was no way of knowing if the vaccine was responsible for his death, but in any case he would certainly have died if he had been exposed to chicken pox in the community so their decision for him to have the vaccine was a necessary decision. Other parents also commented that asking someone from the team about the decisions they were questioning helped put their minds at rest.

Another couple also talked about their experiences of deciding to withdraw life support for their child. He had experienced a sudden and unexpected event with a major bleed and was rushed to Monash as the paramedics said he would not make it to the Royal Children's. He was treated for different things by the two hospitals so was known to both. His mother said, ***"We wonder if he could have been saved if he had been at RCH, but then if he had died there we would have wondered if he should have gone to Monash".*** This couple went on to speak about those last hours and the decision to stop treatment. Their son's heart had stopped several times and CPR had been performed. ***"I didn't want him to die with people pounding on his chest".*** His mother said she knew he was gone as he always slept with his eyes partially open but ***"his eyes were completely shut. That was a way of knowing he'd gone… You could see on the monitor his heart had stopped even when he was still on the ventilator".***

For another couple there was not a decision to turn off the life support but not to put their child on life support as he was deteriorating and dying. For the parents this decision not to resuscitate was difficult and felt like it was made by the hospital. Every other time their son had deteriorated there had been some urgency to get him to ICU, but this time there was no urgency. This mother shared some of her memories of her child's death – ***"I remember thinking that when he was in ICU he could die, but that he couldn't die on the ward… He was dying in my arms, I had seen him struggle but not that far gone… I felt bad, the urgency had been lost… everyone was powerless".*** At this most awful time she was also thinking about her husband and felt maybe he had not realised that the decision not to re-intubate their child had been made and maybe he didn't have a voice just then as his child was dying. She also told us that she didn't know what dying would look like and what signs she should be looking for.

For many of the parents in the group there was no decision to be made about the place of their child's death, but some had the opportunity to make this decision and had decided to take their child home. For these families there was the wish to all be together as they had been separated so much while the child was in hospital. While being at home has its advantages it can also put a lot of responsibility on the parents, especially if they do not feel fully informed of what the last moments will look like. One parent described her experience of her child's last night – ***"It was difficult watching him that night – I didn't know what the signs were. I couldn't wake my husband. I wanted to ask what to do with the morphine but didn't want to leave him to make the phone call. I wanted him to be comfortable but I also wanted to have some words from him. The oncologist had given me his mobile number and said I could call any time but I didn't want to wake him at 2 in the morning. I felt very alone. It went on all night. My baby woke up and everyone was awake – then 10 minutes later he made that decision".*** Another parent who chose to take her child home told us he had relapsed close to Christmas and it felt right to all be at home. ***"We had a whole month at home. It was relaxing. For me the decision was right".*** This parent expressed what many parents also felt, that even though they knew their child was dying – ***"I just kept thinking it would reverse and he'd get better".***

Many of the parents in the group felt that their child made the decision about the timing of their deaths. When discussing the feeling of powerlessness at the end one parent said ***"The power shifted to the kids".*** One parent told us how many people had commented on how tired her child was in the weeks before she died. ***"They said she was tired. Her little heart was so tired. The last photo, it doesn't look like her. She had the power, she said 'no more mummy', it was her decision".*** Another parent told us that they had taken a video of their child on a ride on the day he became suddenly unwell and was rushed to hospital. At the end of the video he looks at the camera and waves goodbye – ***"That's his sign to say he's done".*** Parents found it very reassuring to know that their child had the power to make this decision – ***"If they are going to leave this earth, they should decide".***

A family who attended this group had lost their teenage son to suicide. He had been battling depression for a very long time and had sought help from a number of professionals over the years. His life had become unbearable and in the end he too decided the time of his death. Mental illness is not always understood, but it is no different to the physical illnesses many children suffer. The family told us ***"You always wonder if you could have done something more. He was taking medication and was doing well – eating more, going for walks with his mother. One day he went to his parent's room and flipped through all the photos of himself… He got to make that decision".*** We learned that in the last year or so he had stopped thinking food tasted good, his joints all hurt and he only ate because he knew he had to, his gums used to bleed and he did not have the energy to even get up. His sister told us ***"One decision they question is the last medication – it gave him enough energy to get up and find a train track".*** Like other parents they felt they had not been given enough information, and did not know about the risks of the medication.

The decisions to be made after the death were also extremely difficult.

One couple whose child had died in hospital decided to take their baby home. They had him embalmed so they could keep him at home for as long as they wanted to. Again, this parent felt she was not fully informed about the embalming. For instance, she did not know that they would not be able to bath him once he came home. Like many of the parents in the group, they chose a funeral director with no real knowledge of how they operated. She was very distressed when the funeral director pressured her to organise the funeral quickly as she told her the baby was deteriorating. ***"She seemed more stressed than me. I wanted to say – '*****this is my child'*****. I let her make the decision because she said he was changing rapidly. I had seen him die in my arms – what could be worse than that?"*** This parent has subsequently discovered that there is no law that limits the time you can keep your child at home. ***"I wanted to take him for a walk. She didn't give me a clear answer. I regret not asking other things. I remember thinking 'Why didn't I?'".***

Other parents also talked about the difficulty of choosing a funeral director and making all the decisions necessary for a funeral. There were mixed experiences in the group with funeral directors. Some parents had friends or relatives select or recommend the funeral director for them. One parent told us, ***"We were lucky, our funeral director gave us suggestions. I don't think there was anything I wish we hadn't done".*** Decisions about funerals are so important – what company, cremate or bury… ***"You only get to do it once. I remember going to the florist, I remember thinking I will never come in with my daughter to order wedding flowers, so this is her day, this has to be perfect. There will never be an 18th, a 21st or a wedding".*** For many parents it felt unreal planning a funeral, choosing a casket, choosing flowers for their child. Some parents said that it still feels unreal. They still cannot believe that this happened to their child, to them. It is not that you don't know your child has died, it is just hard to believe that this thing has happened – ***"Six years on I can't get my head around that".***

Parents were asked how they manage to live with or come to terms with their worries about some of the decisions they had to make. One parent said they try to flip the negatives. Believing that your child made the decision that it was time to go helps. One parent said ***"I let my mind pick its battles. It did happen, I can't change it, I have to keep living".*** Another parent said ***"The thoughts don't consume you as much, but they are still there". "There were so many good decisions. It is now a year and a half in and we can slowly start to acknowledge the good things that remind you of the good choices rather than the things you can't change".***

Some of the parents in the group said they now struggle to make any decisions. ***"I have to consider all the angles in any decision. It is very frustrating for everyone. It can be paralysing".*** Another parent said, ***"I'm done with making decisions".***

There was some discussion about beliefs about where the child is now. One couple said they seek support through religious beliefs. They said they are trying to work here to ensure their son's soul is in a better place. Another parent agreed that her beliefs are very important to her. Some parents said they believe in predetermination – that the life span is already decided. ***"Every little thing happens for a reason. Something inside helps me and gives me the strength. My child wouldn't want me to be unhappy".*** A family who believe in reincarnation recommended the following book which they said gave them much comfort: *Many Lives, Many Masters* by Dr Weiss.

As the group drew to a close parents spoke about the ongoing relationship they have with their child. The feelings of many of the parents were summed up in these sentiments – ***"I miss her every minute, hour, day – grief books say the relationship exists but it changes – she's still a big part of our family. The relationship is different. She is not here physically but she is still a big part of who I am. The relationship is ongoing – until I've got her in my arms again. The relationship is intensely personal. We each have a relationship with her, but each relationship is very personal".***

Thanks to all the people who attended the group and shared their experiences and insights openly and honestly with the group and, through the group with all the readers of the newsletter.

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The Royal Children's Hospital
has an annual memorial service
for families who have lost a child.
This is held in August.
As part of the ceremony we have
a bereaved parent speaker,
who shares some of the story of their child.
We are looking for volunteers
who would like to share their story.
Here is a comment from bereaved parent,
Claire, who has been a speaker
at this service:

"I felt extremely privileged to have been asked to speak at the RCH Memorial Service back in 2014, as it gave me the opportunity to share Sian's story with other bereaved parents and their families (and who doesn't like to talk about their children!). Whilst the thought of speaking in front of a crowd can be quite overwhelming for some people, I can honestly say that once I started speaking about our precious and much loved Sian, my nerves just disappeared, and by the time I'd finished, I felt so empowered and proud. And I just knew that Sian was so very proud of me too! It's an experience that I will treasure and hold close to my heart forever."
Claire Wilson – mum to Sian

If you are interested or would like
to know more information,
please contact Paul Hammat:
paul.hammat@rch.org.au
Tel: 9345 4699

Straight from the Heart

Thank you to Stella and Scott,
mum and uncle of Rafael for their contribution.

Raf

You taught me
Patience
That our world
Is meaningless
That pain and
Non-existence
Is nothing to fear
That we're not as rare
As we believe
And yet we absolutely are!

And you looked around
The world in a quiet
Dream often wondering
How it might work??
The people that move around
Look like aliens. How do they
Float so when I can barely be?
So much happiness
I don't understand it
Still there must be
Something in it
But I prefer to dream.

And the days seem to get longer
But there's no use in any anger
It destroys lives but the cancer
Seems to stay, it will just linger
Or so it seems, until one day
It loses patience and wakes
From its slumber where
Its dream has such power
And just zaps me or something
Knowing this makes a life of
Quiet reflection somewhat
Real and retiring, I'm tired
Let me sleep now…..

And I walked in one day
And you were in a painful way
And you winced when they
picked you up
And you cried when you were held
Because you were sad that it hurt
To be picked up and
that you weren't
In a fit state to be
Though you wanted to be
And you cried when they
Told us though your mother
Stayed still and said 'No treatment'
And swallowed then said 'Okay.'
Leaking tears from her
Exhausted eyes
But then she looked at you
Brimming with mother's love…

It wasn't until
The woman with God
On her shoulder
Rambled her way into
The hospital
That she heard
Reality call
And she wept
Until tears
Soaked her face

Then we waded in the water
For the day was much hotter
Than it seemed inside
And we intermittently cried
Because we were saying
goodbye
To someone we loved
very much

And you were
The strongest man
I've ever met
Living sometimes
With no breath
But always a smile
And a laugh and a giggle

And we were friends
We shared moments
In the hospital
Talking about family
And life and love
And dreams of a future
That only ever occurred
In our imaginations
But I remember when
You were older
Because I held it in my mind
And you always seemed wiser
Anyway because you
knew pain
And how to endure
Something it takes some of us
A life-time to learn
You knew it from the start
What a privilege that
you taught
It to me and now I am changed
And I'll never be the same.

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 19th April
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:

"How do we talk to children about death, and about our own grief"

Please join us in April

The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating, guiding the group discussion and writing the newsletter and to Emily Ginger 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

The Royal Children's Hospital Melbourne