FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department



NEWSLETTER SEPTEMBER 2018

Welcome to the September 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.

"Expressing emotions through music"

The group was a little different this month as we were privileged to have Melina Roberts, music therapist guiding those present in using music to express grief in a way that words often cannot. We were also pleased to welcome parents, a grandmother and a close friend to the group.

As people introduced themselves and their child we found that, as is usual for the group some children had lived very short lives and others a little longer, some had been born with serious health

conditions and others had been healthy and had died suddenly as a result of an accident. Regardless of the length of time child lived or of the reason that child

had died, everyone in the group, parents, grandparents and friends all shared the experience of profound grief that the death of a child brings.

Mel then introduced herself and described the to her group understanding of how music can help in the expression of grief and in the struggle of trying to live with such a profound loss. Mel explained that grief is complicated, multifaceted and ongoing. You don't get over grief, she said, you adapt to fit the grief into your life so you continue to function. The loss of a

child challenges our beliefs about life order – our children should not die before us. She said she heard someone talk about grief as being like living in another country where

everything is strange, the culture is different and the language is unknown. Although Mel is not a grieving parent herself, she has some understanding from her work of how difficult it can be to put such strong and complicated feelings into words. She has heard grieving people say 'there are just no words to describe it'.

Mel assured us we all have rhythms inside us and sadly many of us have been put down by a teacher, a family member or friend, someone who said 'oh my gosh, are you tone deaf' or 'don't give up your day job'. Comments like this can shatter anyone's interest in creating music. This is not the case in many cultures where everyone is considered to be an artist and

creativity is the norm rather than the exception.

Mel went on to explain that music is a powerful trigger for validating our

emotions, or evoking emotion, or changing our emotions, or releasing what is inside us. Probably since the beginning of human existence music has been used for healing and to create a connection with our spirituality. It has now been shown that music does impact on health and on our brain. The rhythm we feel in music can help regulate our brains, can affect our mood and emotions and can build resilience. Mel then invited the group to

explore the instruments she had brought along, to have a play with them and then to select one to use in the group. She explained there were no rules about the music we were invited to create, no right or wrong, no need for previous musical skill or experience and no pressure to play any instrument if it didn't feel comfortable.

Mel had brought a collection of different drums and drumsticks and some tambourines for people to play with. After some exploration and testing out of the instruments, some laughter and some hesitation everyone selected an instrument and returned to the circle. Mel gave people some time to explore their chosen instrument and the opportunity

to change it if they wanted to.

When everyone was ready Mel encouraged us to play along with the beat of a well-known song – 'We Will Rock You' and then to follow her beat as we all

became more familiar and comfortable with the instruments. Mel then invited people to close their eyes and think about how they were doing now – how their day had been, today, last weekShe then encouraged the group to play this out on the drum or tambourine they had chosen, each person playing their own rhythm. After the playing came to a natural conclusion people were invited to share their reflections on this exercise.

One parent said, "I tried to find a rhythm but nothing worked. felt like chaos. I think that's how I'm feeling anyway - out of control, especially on these nights. I feel rampant and out of control. I get anxious just coming to this building and I couldn't control it". Another parent described their way **"I was** experience this focused on myself and didn't hear the others - that sounds bad. I wanted to start slower but it was fast and I wasn't sure what tune I was playing". This experience of not knowing what tune you are playing seems to be common with grief, there is often no tune or rhythm to follow. One mother shared her experience of playing a

drum: "I am not a musician at all, it comes from the heart and that's what makes it beautiful.

I listen to music and it makes me cry. I feel it in my heart, and with my

son on life support I never felt I let go of his heart and I feel his heart always. It's always with me". The experience of feeling the vibration of the drum skin brought this experience of holding her son's heart closer. A fourth parent commented, "I felt mine was loud. He (partner) said it was loud in his ear".

Mel then suggested another exercise. She warned the group that this might be a more difficult exercise but encouraged them to try it if they

c o u l d .
People were
asked to
close their
eyes again
but this time



to bring to mind a time since the death of their child when someone had said or done something hurtful or insensitive, something that made the pain worse or made them angry. The group found this a more difficult exercise to get started. One parent said "I am afraid I would put a hole in the drum". Another commented, "I could do it, it would just be really loud", and another said, "If it helps one

person in the room I say we do it". Mel assured the group that if they felt their anger was so strong it would break the instrument that was absolutely fine; she didn't care if an instrument was

broken. She also said that loud was fine. There was no one around who we were going to disturb. She then counted the group in and the group played out their anger and resentment.

Once the playing ended one parent told us what she had been playing out. She said she felt the instrument she had chosen could not do her feelings justice – it needed to be "a million times louder".

This is what she shared with us, you used the resentment that is exactly what I felt today. My mum is really ill now, but she was never there when my son was ill. Through all his 10 months she was never there. Today I told her I resent that. She never looked after me and she is my mum, but I am looking after her. Afterward I had an anxiety attack in my car and nearly passed out. How do you explain to someone who is ill and dying that you are really angry at them. It makes me pissed off. And how do you tell someone who doesn't respond and doesn't say anything?...It's like a rattlesnake, the resentment builds up and then it jumps out of vou. It's like that".

Another parent described what her life is like now: "It's so hard. I'm only 6 months in; I have a lifetime to go. Grief is like a rollercoaster, it's not linear, I know that. You have days that are lighter and then you have days that you are so f***ing angry. I've never had depression, I've been a happy person, but now how do you shift that energy? I used to go running and he would go running with me. walk, like crawling before you can walk - but how do you shift that energy? I used to love cooking and he would cook with me and now it's a struggle just to cook breakfast for the family. It was traumatic, we suffered a trauma, and how do you make the world safe again?......People don't know what to say, but sometimes they say shitty things and that one shitty thing stays with you...People don't cope with grief in our society, they want you to be happy. They ask 'isn't she a little bit better?' How do you shift that energy? They want you to be better".

A parent told us about how anger had impacted on him after his child died: "I had feelings of anger and frustration, of not being able to redirect that anger, and was affecting physiologically - I had aches and pains and it started to scare me. Of course I was affected emotionally and I am changed emotionally. had to make a conscious decision about how to manage that anger. Some days it's 1 forward and step 3 learning to manage that anger and making conscious decisions not to let it impact on my family and on my other son. better at acknowledging anger".

It was clear that anger is a very



present emotion in grief and that it can feel overpowering and frightening. Even expressing such strong emotion through music felt scary for some.

Mel then suggested that the

group close their eyes again and think of a time, an event, a place, a comment that



has been helpful. Once people began to play, the overall sound was quieter and had a very different feel that the previous playing.

A parent told us "I think for me I was trying to think of a break in the beat. I was doing this today when I called (partner) at work when I was having a panic attack. He said to me that our son would be really proud of me".

The final exercise for the evening was to think about sending a message to yourself in the future. It was acknowledged that grief is a forever thing. It is ongoing even though it can feel different at different times. Thinking about yourself in the future can be very difficult when you are just trying to get through each day.

After the group played this out a parent told us what she had been thinking: "I found my beat that time was quiet and steady. I like to think I'm 10 years down the track and that things

will be steady. That all the memories will still be there, the good things and the bad things and all the things that made him. I don't want that to go away, because that pain means I

am still connected to him. I like to think I was more in tune with others

because this is such a solo journey and I want to be more in tune with others".

Another parent shared with us her reflections on the evenina. "It's been different tonight. grew up in a house where music was always playing. music a lot and used it to mood change my at times. After my baby died I related to a particular song. I remember not listening to music when I was driving to work because a song could come on and I would be a blubbering mess. The song I connected to is not a popular song so you don't hear it on the radio but it is on my phone and sometimes randomly comes on and





I still connect to it. I use music a lot. If I want to cry I know what music to put on and I know what music to use to shift my mood. Me and the kids

often have dance parties in the lounge room. When they come home grumpy I say 'come on, we need to dance this out'. I never thought of playing music myself, of playing out my moods, but I guess I can do that too".

As the instruments were put aside Mel asked if people had special songs that they felt connected them to their child. Everyone in the room agreed that they did. Mel commented that music is a very powerful way to evoke memories and to build connections to loved ones. She encouraged people to

join drumming circles and to find ways to express themselves through music if they had found experiences in the group tonight helpful. We thanked Mel for coming to the group and for sharing her knowledge, her skills and instruments to provide an opportunity for everyone to try another way of expressing their feelings. A participant thanked Mel for her empathy and understanding. This group had been a bit different and had provided a powerful opportunity to share the experience of grief and feel that perhaps the journey doesn't always have to feel quite so like a solo performance. You may not feel like you are part of an orchestra but perhaps there is a band you feel at home in.

Many thanks to Mel and to all the people in the group who took a risk and participated in music making.



Straight from the Heart



Thanks to Bernadette Houghton for her contribution.

Last night, when I went off to bed, Your photo I walked by. And I thought I saw you smiling From the corner of my eye.

I went back for a second look, And you were smiling fair; But it was not the jolly grin I'd thought that I saw there.

I moved away with one more glance,
And saw you wink an eye;
I doubled back and looked again,
Back at my darling guy.

Once more, you smiled with innocence, From down upon the wall; I stood and stared at you again -You didn't move at all.

Could it have been a trick of light, Had it really happened? Was it all just wishful thinking, Something I'd imagined?

I looked once more at that photo, And swear your smile just grew; And did you lift your head an inch, When I glanced away from you?

I looked at you again so deep, I held your eyes with mine; And once again your smile, it grew, As if giving me a sign.

A sign to let me know you're near, And watching over me; That you are well and happy and Your spirit's running free.

I looked once more straight at your smile, But it was still again; I turned aside, looked straight ahead, And saw you grin again.

Although you are with me no more,
It is not a goodbye;
I know that I can still see you
From the corner of my eye.

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 18th October 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:

"What do you think professionals should know about caring for the dying child and their family?"

Please join us in October

The newsletter is always a team effort.

Thank you to Melina Roberts for facilitating, to Helen Stewart guiding the group discussion and writing the newsletter and to Leah Robinson 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.