

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER APRIL 2022



The Royal
Children's
Hospital
Melbourne

“Different expressions of grief – how people grieve differently and the challenges of this in a family or relationship”

We had a small but very worthwhile group this month, no doubt due to school holidays and public holidays. Three people attended from 2 families with different experiences of their child's death. One child died suddenly and unexpectedly and the other 21 months after a cancer diagnosis. Despite these different experiences they had a shared understanding of the enormous impact of the grief of losing a child.

As the anniversary of the death of one of the children was approaching, we discussed the difficulty of anniversaries and the lead up to them. One parent told us she always uses a calendar which you flip over every month. She dreads the end of April when she flips over the page to May. This parent told us that she wanted to attend the April group as she is still feeling okay in April. She spoke of the build up to the anniversary and the days surrounding it: **“Sometimes it's the build up which is harder than the day itself. It's the movie playing in your head, you can see the day your child died in your head”**. The anni-

versary for the other child is also approaching. The mother said: **“It's the time leading up to the anniversary – it's coming closer. I'm already sad”**. An additional challenge for this family is the celebration of their youngest child's birthday the day after the anniversary of the death of their oldest child. As one parent said: **“It is always going to be a rollercoaster”**.

The theme of the group was different styles and ways of grieving and the impact on relationships. As we moved on to discuss these issues the parents in the group discussed their differing grieving styles. One parent had separated from her partner since her child's death, and reflected on how much extra pressure grief placed on their relationship. She said their relationship was already a little rocky so was at high risk of breaking down under any extra pressure. She told us that even a good relationship was at risk of breaking up after the death of a child, but if your marriage already has cracks, then it is almost inevitable that the relationship will not survive such a tragedy. She confided

that in her relationship her partner was not able to support her, even when she could tell him what she needed. She said: **“I felt like I was grieving on my own”**. Another couple talked openly about their different ways of grieving and the impact on their relationship. **“Since he passed, we still grieve in different ways. My partner finds ways to distract himself or stays focused on other things. I am still fully in it, intensely grieving and don’t want to distract myself.....I feel I need that time to really experience the grief, think about him, be really sad, and cry”**. The father reflected on how he coped when his son was first diagnosed with an incurable brain tumour. He told us he became a researcher, searching for clinical trials and treatment options. His partner said: **“I could not do this. I knew the answer was there was no cure”**. The father told us: **“I have built a buffer to get through my everyday life. I feel like I overdid the buffer at the start. Now I can shut the grief out and I don’t feel grief everyday....When it affects me, it affects me deeply. However, it happens infrequently. At the moment this works for me”**.

One of the challenges in grief which can be exacerbated when couples grieve differently is the sense of being alone in your grief – **“I feel like I am more alone, even though I am not. I know I am not the only one grieving our son”**. Her partner told us that sometimes he wishes he could give her some of her buffer but he realises that maybe this is not what she needs to grieve. They also reflected that even though they do have different grieving styles and need different things, they both have times of being fully in the grief but usually not at the same time: **“we ‘take turns’ supporting each other and ‘being in it’”**. This is not a conscious, deliberate thing, it just seems

to happen this way. The grieving style that involves researching, organising things, keeping busy and ‘building a buffer’ is generally referred to as instrumental grieving and is more common in men than women.

The question was asked – **“Is the way I am grieving healthy?”** There is nothing wrong with instrumental grieving, particularly when you also have periods of really being ‘in the grief’. Keeping busy, building a buffer is an excellent protective mechanism to allow you to get through your day and often do things others who are more expressive in their grief cannot. In a relationship this balance may be needed to keep the wheels turning and only becomes unhealthy if each member of the couple cannot accept what the other needs at that time and offer support for that person. You may desper-



ately want your partner to take on some of your buffer so they are not so distressed, or you may want your partner to be more expressive in their grief so you can feel they are grieving like you, but you cannot impose your grieving style on someone else.

The grieving styles and needs of individuals may shift and change over time often in response to changes in the partner. It is okay to feel like you need to seek people outside your relationship to help. There is a lot of pressure on a relationship already and part-

ners should not feel like they alone are responsible for the support of their partner. One parent told us that when she realised her partner could not support her in her grief she reached out to her family. **“I was asking him to grieve with me, but he was unable to do this”**

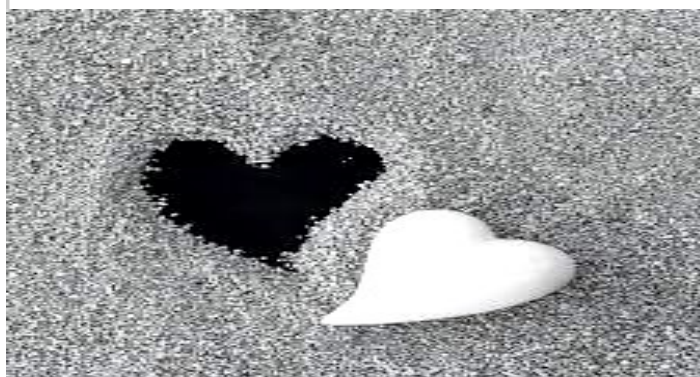
As mentioned at the beginning of this newsletter, one of the families lost their child to a very sudden and unexpected death while the other family had almost 2 years of knowing their child would die.



While the grief of losing a child is the same, the experiences of the death and the lead up to it were very different. When discussing the impact of the anniversary and the memories of the actual death, a sudden death carries a certain set of memories. One parent spoke of her vivid memories of the last day her daughter was alive and well and their ignorance of what was to come the next day, the event itself and everything that happened over the next few days until her daughter was pronounced brain dead and organ donation occurred. Everything happened in a very short space of time and there was an intense need to understand what happened and why and to find someone or something to blame.

In a situation when the death is expected, the long period of anticipating the death is very difficult – living each day knowing the days are limited – **“It was a long stretch for us, we cannot define one day in a 21 month build up.....I started grieving for him 21 months before his death, even though he was still there, I knew he was not going to be – it was such a strange time”**. There are many layers to grief and when the death is expected the grief starts sometimes many months or even years before the child actually dies. In a sudden death, initially the shock of the

death, the disbelief that this has even happened, may overshadow the grief in the initial weeks. Parents spoke of searching for a reason – when the death is anticipated this may happen when the child is diagnosed – **“Was it because we bought a microwave, mould in the house, too many hot dogs”?**, while in a situation of a sudden death this search for a cause, for someone or something to blame comes after the death and may dominate the early part of the grieving **“I was angry, in those first weeks I remember calling my dad and questioning everything that happened.....I wanted someone to blame”**. For the parents whose



child had died from a brain tumour there was also the immense grief of seeing their child deteriorate and lose his ability to move and to communicate. Watching their previously vivacious and healthy child change so much was an enormous grief. All the parents reflected on the challenges of seeing their other children or their children’s friends and peers reach milestones their child was never able to achieve. One parent said: **“I was shocked to see how big his friends are now”**. Seeing how the world moves on without your child in it can **“take our breath away”**.

We also looked at how other family members grieve and how they are coping with the loss of their sibling, grandchild or even great grandchild. One parent spoke about her son who is now a young adult. She said



he never talks about his grief although he does talk about his sister. She told us that when he was younger she tried to hide her grief from him. She talked about his sister to him a lot, but did not talk about her grief or openly grieve in front of him – she tried to protect him from this. Now he is older she does let him see her grieve and talks about this but she feels he is uncomfortable with this. On his 18th birthday she said to him – **“I wish she could be here for your 18th birthday mate”**, but he did not respond. He was 9 when his sister died so has many memories of her. For the other couple this was not the case – one sibling was very young and the other sibling was born after her brother died. They wondered how these children would know their brother. Another parent shared her experience of her daughter’s young cousins who were too young at the time to have genuine memories of her. She told us that in the early years when they celebrated her daughter’s birthday one of the young cousins thought this meant that she had returned. She said: **“Her younger cousins have grown up knowing her, even though they cannot remember her.....she is still part of the family”**. The parents of the other child told us that their now 4 year old asks about his brother and what happened to him, he is still part of the family.

The experience of the grief of the grandparents and, in one family of the great grandparents also varied. The great parents found it very hard to accept that they were still alive while their healthy granddaughter had suddenly died. While this was very understandable and was a question the parent also had – **“it is not in the right order, we shouldn’t be burying our child and particularly not our grand child and great grandchild”**, this response of the older generation was not particularly helpful to the grieving parent, although they too had these questions. She also told us that her father

talked about what had happened in the early weeks, trying to make sense of a senseless situation and was really supportive of her in her search for understanding also, but later he could not talk about his grandchild and continues to be like this. Initially she found this very distressing but now understands that it is just too painful for him.

The other couple had a different situation with the grandparents, like them grieving while their child was still alive. One set of grandparents moved in with them for the months before the death. They were very helpful in looking after the sibling and the parents, but found it very difficult the care directly for the child. Their presence, however allowed the parents to be able to fully care for their child. The other grandparents found it very difficult to accept that nothing could be done and searched for possible treatments and cures. The father reflected that his parents found it increasingly difficult to come and see their grandson – **“their beautiful grandchild basically became**

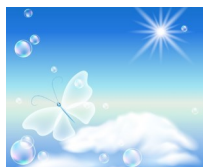


unrecognisable in a short time. This was just too hard for them”. Even though this father could understand why his parents did not come more often, it still hurts. Grief is multilayered and complicated. Parents have no choice but to confront their child’s ill-

ness and death, however much it is unfair and inexplicable. Grandparents have their own challenges witnessing their child's grief as well as their own grief for their grandchild, and perhaps dealing with their own uncertainty as to how to support their child and manage their own grief.

The couple in the group have been considering moving overseas to be with the mother's family and told us they would have done this if their child was still with them. They spoke of the challenge of moving not just to another house but to another country where their child had never lived. They still sleep in the bed they shared with their child in the last months of his life – he was right there in the bed with them. The other parent in the group had moved house after her child died and spoke of how very difficult this had been and how she adapted to this. She has a room in her home which she has set up as her daughter's room. She has painted it her favourite colour and has all her things in it. She said: **“She is in your heart, wherever you move, wherever you travel she always travels with you”**.

Although this was a small group, we discussed many significant issues and the parents were very generous in sharing their grief and their vulnerabilities in this grief. We hope some of these experiences resonate with you and help you to feel less alone in your grief.



*I loved you your entire life and
I will miss you the rest of mine.*



You will forever be my always
FOREVER YOUNG

Our letter box is Waiting!



Contributions such as responses and reflections on the groups' themes, poems, letters, songs, reviews of books that you may have found helpful, 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

The next meeting of the
Family Bereavement Support Evening Group (Via Zoom)

Thursday 19th May 2022 at 7.30pm

Please join us to discuss the topic:

“Living and Remembering”.

If you wish to attend this group please
email: Bereavement.Services@rch.org.au



The newsletter is always a team effort.
Thank you to Helen Stewart for facilitating the group discussion and writing the newsletter,
Thank You to Grace Jury for scribing parents' statements.
And thank you Marina Puljic for ensuring the
newsletter is formatted, collated and distributed to interested people

Social Work Department, RCH



