

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER JULY 2022



“Understanding grief—am I normal”.

This group was once again held over zoom with a small attendance but rich discussion. In this group we explored current understandings of grief and the relevance of these theories to the lived experience of the grieving parents present.

sets out 5 (later 7) ‘stages’ of grief, beginning with Denial then moving through Anger, Bargaining, and Depression to Acceptance. It is worth noting that this theory was developed through conversations with dying people, not with the bereaved and that Kubler-Ross



A well-known theory about grief is the 5 stages of grief developed by Elizabeth Kubler-Ross in 1969. This theory

did not see it as a necessarily linear process. Parents in the group agreed that denial is definitely present in the first year – **“I was looking for the why. I’m a**

good person, why did this happen to me? In the second year I realised this had really happened, she was never going to come through the door again". The group was also in agreement that they will never get to acceptance. A parent said: **"I am never going to accept that this is okay. I can't picture a moment when I feel it is okay that my son passed away"**. A parent in the group talked about life growing around the grief. The grief doesn't go away or even get smaller as time goes on but life does grow around the grief so the grief does not consume such a big proportion of your life. Another parent commented that grief does not happen in neat stages. She described grief as a tsunami. You can be standing in calm, shallow waters, then all of a sudden something triggers a great tsunami of grief and you can't find your way up to the surface, then the waters calm again. The tsunami is unpredictable and overwhelming until it calms again.

The second theory or understanding of grief we discussed is the dual process model where the authors, Stroebe and Shut (1999), describe a dual process where grieving people move back and forth between what they call 'loss orientation' and 'restoration orientation'. In the early times people are more often loss orientated where they are immersed in their grief and unable

to think about changes and life outside their loss. They do still have moments of being in the restoration orientated space and attending to life changes, doing new things and being distracted from their grief. As time goes on many grieving people tend to spend more time in the restoration space and less in the loss space although this will vary greatly from day to day and person to person. These authors also say that grieving people need time out from their grief, even very briefly. The people in the group did not really relate to this model very strongly. The description of grief as a tsunami fits with this concept of moving in and out of loss orientation. A parent whose daughter had complex health needs since birth and lived until she was 15 spoke about anticipatory grief and about the 'readiness' for the loss. **"You would think that I would be ready, but I never really did believe she would die, and I just assumed that things would get better. It was a reckoning"**. He also spoke of anticipating loss and his experience of this – **"I experienced anticipatory grief – the anticipation of things going wrong all**



the time creates a lot of grief". In rela-

tion to being restoration focused he said: **“I try to reframe my life intentionally, trying to stay present. Another daughter is a high motivator to stay present”**. Another parent also spoke of the intentional decision to live life to the full and to live a good life as part of honouring her son. She also commented how hard this was in the beginning and can still be at times.

Worden’s 4 tasks of Mourning, articulated in 2009, provide us with another way of looking at grief and grieving. Worden based this theory on adults who had lost a spouse. He proposed 4 tasks although they are not necessarily sequential and may be re-experienced over time. The first is:

To accept the reality of the loss.

Parents talked in the group about the difficulty of accepting that their child was really gone and really not coming home again in the early days of their bereavement. The loss of a child is not just one loss but so many losses. As one parent said: **“You lose all their future, all the things they would have done and would have been, all the milestones they never achieve”**. *Accepting the reality of all these losses can be an ongoing task as the years go by .*

2) *To work through the pain of grief.* There are many emotions associated with grief and the loss of a

child. Some of these emotions are difficult to talk about and people are not always given the permission to talk about difficult feelings. Parents sometimes experience guilt – did I do enough....., anger, despair, sadness, even sometimes shame or relief. All these and many other feelings are legitimate and cannot be understood and dealt with if they are not able to be expressed

3) *To adjust to the environment without the person.* In the group we talked about how hard it is to adjust to the ordinary everyday things in your life, like sitting around the dinner table with one less person – all the things you take for granted. **“You just take that for granted...sitting around a table with 3 when there used to be 4. There is always someone missing”**. Another parent spoke of the Royal Children’s Hospital and the part this place had held in their lives – **“I have a love-hate relationship with the RCH – a place where my daughter went so often and where she had her last breath”**.

4) *To find an enduring connection with the person while moving forward in life.* Parents in the group talked about the ways they keep their connection to their child and compared this with the experience of earlier generations and with some people in different cultures. A parent spoke about the experience of a great grandparent losing a

child – a fact she did not even know until she lost her own child. **“They didn’t have the things we have now to support their grief, they only had 1 photo while we have photos all over the house. They were not able to talk to their family about the grief – it was almost taboo. We have counselling support nowadays”**. Another parent said – **“I can’t imagine not mentioning my child’s name daily. To not include her in our conversations is denying who I am. You are just turning off”**. And a father said: **“She is always going to be part of me. She is in me. I don’t think we are meant to get on with it”**. Having an enduring connection with the child was not only seen as essential by everyone in the group, but it was also seen as inevitable.

There was some discussion about how much harder grief is when the death is considered against the natural order of life as in the death of a child. It is felt in the literature that this is one of the risk factors for complicated grief. People in the group felt that there is a different kind of grief when a grandparent passes away, the grief cannot be compared. When an older person dies you lose the shared memories, when a child dies you lose the future, all their milestones, all the firsts. The losses keep accumulating as time passes. One parent said: **“This is an unnatural process, an unnatural death. Maybe that’s why**

this is so much harder”.

The final theory we discussed was one by Robert Neimeyer, ‘Reconstruction of meaning’ where he discussed the importance of making meaning in loss. The idea of finding meaning in the death of a child was a difficult one to grapple with, as the death of a child seems so senseless, however the idea of finding new meaning or different meaning in life as a result of the child’s life made more sense. Neimeyer says that time does not heal, it is meaning making that heals. A parent said: **“Time alone doesn’t help; our world has been ripped apart. It is a conscious choice that we do something with our lives to honour our son”**. This parent went on to talk about how difficult it has been at times to honour that commitment to her son and how it often required a very conscious effort. She told us that the lockdown we experienced in Melbourne made it difficult to honour the promise to always live life fully and make lots of memories as, for them part of living life fully included travelling. In order to do this when they could not travel more than 5 km from home the family had a great time pretending to travel to Mexico. She told us that this enabled them to make some positive and fun memories during a very difficult time and **“is our way of making meaning”**. People in the group spoke of the realisation of

the lack of control we have over our lives when a child dies and the impact of this on the way they live their lives. Some of the things parents said about this were: **“I think I’ve got control, but actually I have zero control – the biggest lesson my son taught me”**. And another comment: **“I can relate to the idea of seeing the world as a safe place, but it’s actually not safe – it’s so sobering, of course the world is a dangerous place”**. Others commented on the fact that just because one horrendous thing has happened to you doesn’t mean another equally horrendous thing will not also happen. Knowing these things can help people to finding meaning in their lives and to constantly make memories. **“You make the most of the moment because you don’t know what the next moment will be. It is either you do this or you always fear that something is going to go wrong”**. A father said, **“I am just present, I try to be present all the time”**. A parent spoke of feeling obliged to her child to live her life really well.

One of the parents in the group was the father of a child with additional needs. He talked about his journey with his daughter and with his grief after she died. He told us how he stopped comparing her to her twin sibling when she was young and started to see her for who she was. He accepted that this was her journey. At one time

he spent about a year and a half modifying a caravan so the family could go on holiday together. In speaking of his current situation, he told us: **“At least it’s part of my journey now – I don’t want to sabotage my other daughter and live on the edge to anticipate that something bad is going to happen all the time. How do I do this new life which is so much worse than the old life – by accepting that something could happen today, but I’m just going to try to be really present and live life to the full.....She taught me in the beginning the determination to make life work. I like the person I have become because of her and I wouldn’t like to go back to the person I was before she was here”**. This sentiment of not wanting to go back to who they were before their child was born was shared by all. If you had a choice, would you still sign up to the pain of losing a child? The answer was ‘yes, if the alternative is to have never had the child’. All the pain was worth it to have known the child. One parent expressed the thoughts of all when they said: **“Grief is the price we pay for love. We are grieving so much because we love them so much”**. All the parents felt they had been changed by their child and their life, no matter how long or how complex or fragile. All the children had added meaning to the lives of their parents and their lives were different than they would have been had the

child never lived. There was immense meaning in the lives of each of these children.

While there is no formula for grief, the various theories and understandings of grief in the literature discussed in this group all contained something to which the parents in the group could relate although none fully described what is perhaps an indescribable experience in the grief of the death of a child. I would like to thank the parents present for their insights and the honesty of their sharing. I hope this newsletter has been helpful and meaningful for those who receive it.



*Since the pandemic stopped us from running groups on site at the
Royal Children's Hospital*

we have transitioned to a zoom format.

*Unfortunately the zoom groups have not perhaps held the same appeal for
parents and have not been as well attended as the face to face groups were.*

*It may still be some months before we are able to hold meetings on site again
and while we wish to continue to support the community of bereaved parents
who attend the groups and read the newsletters,*

it is not feasible to run very small groups going forward.

*In order to keep the groups sustainable and optimise the benefits for those
who attend online,*

we need a minimum of 5 participants.

*If you wish to attend a group please let us know and confirm on the Thursday
of the group that you are definitely able to attend.*

*If a minimum of 5 attendees are unable to confirm and attend we will cancel
the group for that month.*

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 18th August 2022 at 7.30pm

Please join us to discuss the topic:

*Being present and self-compassionate in your grief: using mindfulness for daily challenges.
This group will include some mindfulness exercises to start and conclude the group.*

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



The newsletter is always a team effort.
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Social Work Department, RCH



