

**FAMILY BEREAVEMENT SUPPORT
PROGRAMME**
Social Work Department
NEWSLETTER OCTOBER 2023



**“ What has happened to my brain? The impact of grief on the brain
and brain functioning. “**

The October group was well attended with participants grieving children of varying ages, causes of death, and differing times since their death. The topic for the group was about changes in the brain associated with grief. Parents in the group have often spoken of feeling that their brain isn't working in the same way as it was prior to their child's death. More studies are now being done on how grief effects the brain which are consistent with the experiences of grieving parents.



We began the discussion by looking at bonding and attachment and how it changes the brain. At the time a bond is being formed, certain neurons in the brain increase in size and neural encoding is created to trigger a physiological stress response to separation. This process allows us to manage the everyday separations and reunions that occur in life between us and those we love. When a separation occurs, (eg the child goes to school) a stress response is triggered and the brain produces a stress hormone – cortisol. When reunion occurs (eg. child comes home from school), the brain releases pleasure hormones oxytocin and dopamine. When there is a strong bond, the brain is wired to always expect the reunion to come and to seek reunification. Our brains have a mental map of our world which includes our relationships, and this map does not adjust quickly or easily to significant changes in our world. The one we are bonded to who has died is gone-but-also-everlasting. Our brain is still expecting them to return, and the stress of the separation is not relieved by reunification. Grief can be seen as a process of relearning the world, creating a new mental map of a world when your child is no longer alive and will not be return-

ing but is still everlastingly in your life.

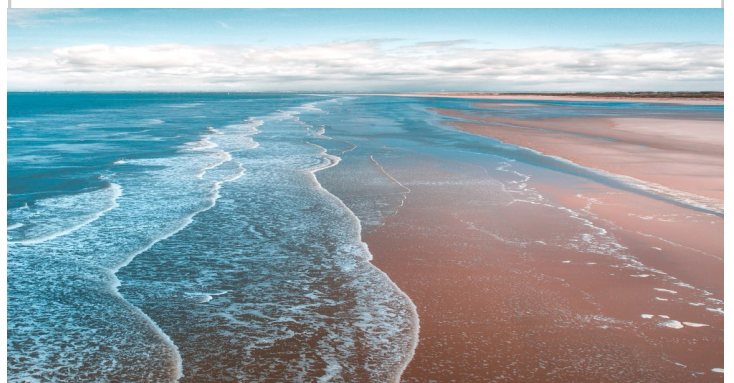
Parents in the group have often spoken of the disconnect between what you know rationally - 'my child is gone and won't be coming back' and what your heart is telling you - 'they can't be gone, they still might come back.' People who are grieving have higher cortisol levels, as the brain releases stress hormones while it continues to anticipate the return of the loved one.

Another change in the brain of grieving parents is in the hippocampus, a part of the brain associated with memory and learning. The hippocampus reduces in volume in parental grief. This change makes it more difficult to learn new things and then remember them. This resonated with parents in the group who spoke about their difficulties with remembering things, with concentration and with learning new things, particularly in the earlier times. One parent said; **"I feel like I am in a fog that seems to be everlasting and all-consuming"**. Another parent told us that after her child had died, she could not read a book as she simply could not take in what she was reading. **"I used to read a lot, but after he died, I just couldn't read books anymore – I would read a page then realise I had no idea what I had just read. I would reread it and get through a chapter, but I could not remember the content at all. This persisted for about 3 to 4 years"**. One of the other parents said she now listens to audio books as she cannot concentrate on reading. A parent has been working at the same place for many years and is very familiar with his job, but since his daughter died, he doubts himself and re-checks things he has done. He said he never finds a mistake but the doubt and need to double check persists. Another parent spoke of returning to her job and being unable to remember her passwords and constantly needing to call IT to reset them. One of the parents in the group has begun a new job since her daughter died. She said she finds

herself asking the same questions she asked when she first started in the job. She said the information is usually not complicated, but she finds it hard to retain. The experience of being unable to hold on to new information or to remember things was common in the group.

Parents spoke of being easily distracted and therefore unable to remember what were doing. **"I would walk into a supermarket and then see a baby and completely forget what I wanted to get or even know how long I had been standing there"**. Many things distract and bring the grief back to the forefront, pushing out other thoughts. Many reminders were discussed. **"The weather can be a reminder, the smell in the air. It can make me feel like I should be somewhere for my child"**. Even the light during the day (e.g. sunrise, sunset) can bring back almost unconscious memories or emotions. Not all reminders trigger conscious or concrete memories, it can sometimes just be a feeling. One parent described it as feeling like a dream. Parents talked about both deliberately going to places that remind them of their child, and of deliberately avoiding places where memories are strong.

As well as difficulty with remembering and learning new things, parents talked about how their brain does not seem to work in the same



way as it did before. A father who was a very organised and busy person before his son died said he completely lost that skill. Even now, many years on he needs to relearn that skill

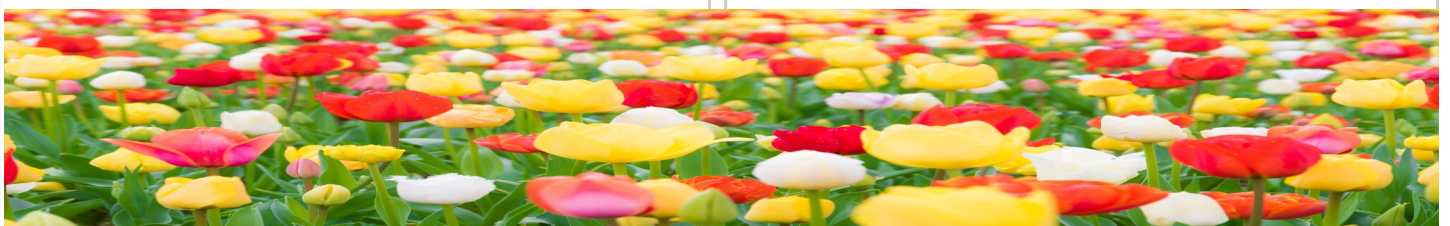
although the family now have a very different lifestyle and the need to have a very structured and organised life is no longer prominent.

Grief has a significant impact on sleep, and this was something many of the parents in the group had experienced. Some found it difficult to sleep and found themselves still waking at the times they used to need to provide care for their child. A mother told us how guilty she felt the first night she did not wake up at the time she would have been feeding her child. Parents commented on how exhausting grief is, even if you do sleep fairly well. A mother said that she had to be really exhausted to sleep well, and the nights she cried herself to sleep she would often sleep better due to sheer emotional exhaustion. She also said she found it hard to sleep without all the background noises of a hospital. Exhaustion can be both physical and emotional. Parents spoke of their lack of energy when it came to social engagements, listening to the worries of others and maintaining half-hearted relationships. A father said: **“I just don’t have the energy for that anymore. We have our children and our grandchildren and a few close friends, but that is all. That is all I can manage at the moment”**.

There was recognition in the group that the death of a child is not just one loss at one time. One parent talked about the impact of having her oldest living child starting secondary school. She told us that she was aware of the time that her oldest child would have started high school but it has only become real for her now they are preparing to have her second son start. She said she has been crying more as she realises all that they and he has missed out on. She gave us other examples in

her life of similar times and the realisation of all the losses – never seeing his handwriting for instance. Another parent spoke of her grief at never being able to shave her son and never hearing his adult voice. Other people do not understand these multiple losses that happen over time, even many years after the child has died.

Some of these losses relate to the loss of who you were and how your life was structured. **“I liked being the expert on my child, I liked being needed”**. **“I always knew what he needed. The staff used to ask me how he was because I was with him all the time and knew him best”**. When your child is no longer there you lose so much of who you thought you were. Other parents spoke of how they missed touching and cuddling their child and being touched and cuddled in return. One parent told us she tries to keep busy and to find ways of being needed. She babysits her grandchildren and knows they need her to care for them, but there is also grief as she sees that her 12 month old grandchild can already do more than her 14 year old so was ever able to. For parents who do not have other young children, having time to be alone, to do things they couldn’t do before, to have time to think and/or relax, feels very foreign and can bring about feelings of guilt – **“It just feels wrong”**. Parents feel guilt when they find themselves feeling happy or just being busy and not thinking about their child for a while. Perhaps some of this feeling of ‘wrongness’ is coming from the brain still seeking the missing person and yearning for the reunion to reduce the stress and increase the pleasure hormones – gone-but-also-everlasting. It is a difficult process for the brain to redraw its mental map of the world.



With the end of the year approaching the issues of celebrating anniversaries and special days was raised. Some parents said that creating rituals helps them to get through these days. The rituals can change over time but remain a part of family life. Several parents agreed that the days that you prepare for often are not as hard as you anticipated but it is the unexpected reminders that you cannot plan for that knock you over. A parent said that it is often the day after the special occasion that is harder. **“You have everything prepared and planned for the day, but the next day the grief hits”**.

A parent shared with us his journey following his child’s death at the age of 6 weeks. He spoke of the feeling of free falling in the early period of his grief and struggling just to try to slow that falling sensation. He spoke of being in a dark place at that time. For him and some of the other parents in the group, the decision to try to move out of the dark place and let some light in was a very conscious but difficult decision. In his case it was largely motivated by the need to care for his other child and not have him hate his brother for making his parents miserable all the time. He said – **“We live in a place of gratitude. We have had a complete change of lifestyle. We have re-focused. Life is very precious, and we try to live consciously and purposefully. We spend our time with people who understand our grief and can be there to support and to hear us”**. He told us he wants to have a positive impact on all people he meets. It is an irony that he would very much love to have his child with them in this life, but if his child had lived, he would still be living the lifestyle they had when he was born. **“It is why I live in a place gratitude. Gratitude that he chose us as his parents and taught us so much in the time he was here”**. Another parent also spoke of having made a conscious decision to lead a full and happy life after their son died – a promise they made to him. It was very difficult in the early years but has become easier over time. One parent

described his life as walking forward in life but sometimes stumbling when something triggers his grief. He can now pick himself and continue moving forward.

The length of time the parents in the group had been bereaved varied from less than a year to over 10 years. One of the more recently bereaved parents asked how things changed over time and did you ever feel like you are moving forward. A parent responded that it can feel like for every step you take forward you take 3 back but over time, with conscious effort, the backwards steps become less and eventually they become stumbles along the way. Grief never goes away but your life can still move on and become rich and joyful.

As we spoke of life moving on, of the brain relearning a new map of the world, parents spoke of their fear of forgetting their child. One of the parents told us that when she was in the early stages of her grief and afraid of forgetting her child, a friend of her mother’s, who had been 40 years bereaved told her that you never forget your child. She had never spoken of her deceased child but intuitively knew that this parent needed to hear this reassuring message.

The discussion in the group and the experiences of the parents present and many before them suggest that the changes seen in the brains of grieving people are indeed real and play out in the experiences of grieving parents. **Gone-but-also-everlasting** is a concept that makes sense to parents and so much of what parents experience fits in with the brain changes seen on MRI’s. I hope this helps parents to understand that they are not going mad when their brain seems to be functioning differently, their brain really is different and will need time and conscious effort to readjust to a different reality.

THANKS AS ALWAYS TO THE PEOPLE WHO
WERE ABLE TO ATTEND THE GROUP
AND SHARED THEIR EXPERIENCES SO
GENEROUSLY.

I HOPE THIS NEWSLETTER REPRESENTS
THE DISCUSSION AND PROVIDES
A SENSE OF COMMUNITY
TO THE PEOPLE READING IT.



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 will be held on:

Thursday 16th November 2023
7.30pm—9.00pm
The RCH Foundation Resource Centre
Level 2, 48 Flemington Road
Parkville, VIC 3052

Please join us to discuss the topic:

Travel and Grief - Can vacations help with Grief?

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 Lizzie McNulty 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



