

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER JUNE 2021



Welcome to the June bereavement group newsletter. We hope this newsletter brings you a sense of connection with other bereaved parents.

"Moving through the world with grief – what things change; what stays the same?"

The June session coincided with a number of difficult anniversaries and events for parents, including Mothers' Day, significant birthdays and anniversaries of all of the children's deaths around this time, with one mother sharing that the anniversary of her son's death was the same week. Another mother spoke about how her son would have turned 16 in the previous week. One mother whose child would have turned 21 this month said: "Every anniversary is hard but this year has been *significantly* hard". In the face of these very difficult times several parents identified that grief itself continues, and does not lessen. Yet, despite the grief being continuous, throughout the discussion parents were able to share how the ways in which they respond to it can change over time: the way they care for themselves, who they choose to have around them and how they manage to find a way of living with grief.

Parents talked about their child's varied journeys. Differing circumstances such as whether the death was sudden or expected, the

age of the child at death and whether there was illness or not during their life, can change the meaning and memories of the experience and feelings surrounding the loss. One mother talked of her son who had had lifelong disabilities with numerous health complications and unexpectedly died at the age of fourteen. Life with her child revolved around care for his illness and disability such that the parents had "wondered how long they could keep going" – but whilst there was some relief at the release of this, she told us how she "would give anything to care for him [again]". Another mother, talking of her fourteen-month-old baby who died from a brain tumour, also spoke of contradictory/mixed emotions, She hadn't wanted him to suffer and the heaviness of her workload decreased after his death but she "would do anything to have [her] crazy busy house back again". Another mother spoke of the extreme shock and trauma of her previously very healthy eleven-year-old daughter's sudden death. Despite these differences in their stories and experiences, parents in the group were able to support and speak to the kinds of



grief and loss responses other participants described.

The facilitator asked about how the group participants have moved through the world with their grief, whether there are changes and is there a consistency within their grief?

Parents spoke of the painful experience of having just lost your child but realising that the rest of the world just continues on, defying the enormity of the loss that had just occurred: "Coming out of the hospital to get fresh air, there were cars driving past, people laughing, nothing stopped. I'm in this bubble; I've been told the worst possible news and life just went on". One mother described how this experience of pain at life moving on impacted on her ability to respond to her husband and surviving children: "I love being a mum; it's the greatest thing I ever did. But I found it hard to be around the older two once I lost [child]. It was so unfair on them, and unfair that he wasn't here.....My whole world was raising kids and then I wanted nothing to do with kids." Hearing her husband laughing with the other children after her son passed away "was a stab in the heart - how could he be laughing with them"? Another mother talked about the experience of losing her child during Covid, and how her encounter with the world "moving on" was delayed because of this: "I felt we had a cocoon to shelter us from the world and when everything opened up I was disappointed - I had a mental breakdown. With the kids back

at school I had to face the world and I couldn't cope with it; I just wanted my cave". She described how in a "normal" situation people provide comfort which can "give a process to death", but there was a gap in this process due to the pandemic, which meant that when she saw people again she was just "launched back into life" with no-one acknowledging the loss of her son. Though no-one said anything wrong this lack of any processing with her was "jarring" and made her feel like her son "didn't matter". Another group participant, whose child had died many years ago and had been able to have a large funeral, described that despite this "as soon as the funeral is finished everyone is gone; they go on with their lives". The world at large doesn't give pause at the shocking loss that has just occurred, and the demands of daily life continue.

Parents spoke at length about their early grief responses as well as what their grief looked like further down the track. Early grief responses included being overwhelmed by sadness, distress and tears and feeling unable to function in their life. One mother recalled "I do remember I couldn't do anything in the early days. I remember leaning on the door frames, leaning on the house to hold me up". She felt unable to get out of bed to do things for the surviving siblings: "I would pull the doona over my head". Though friends expressed amazement that she could even walk or function at all, her own perspective was that she *wasn't* functioning.

Sometimes parents are unable to do what they most need to do straight after their child's death. For instance, financial circumstances or the expectations of others can push a parent back to work before they are emotionally ready. One mother felt forced to go back to her work as a teacher (which also intensified the traumatic grief as her child had died at the same school). "I would cry at recess and lunch every day and then go back to teach. I was present but not there. I look back nine years later and have no idea how I did that".

For many the acute grief is so intense that it barely feels possible to go on. Several parents express that in the acute grief it was only their immediate family that enabled them to keep living. One mother described that after her breakdown, many mornings she did not want to get up, and would think about the trucks going past outside. But hearing her children and husband in the kitchen, she was thankful to have them "to keep going". Other group participants who attended this month related to this as they all had other children and identified this as a huge factor in helping them have a reason to continue in their life. But this can sometimes be "bitter-sweet" as parents watch them grow up and have experiences that their other child never lived to attain. This sense of loss of milestones and experiences never attained can be felt intergenerationally – one mother described the grief of the 90-year-old great grandfather who couldn't understand why his great granddaughter died- "why not me?"- and the great grandmother who cried "three lots of tears for her daughter, her granddaughter and great granddaughter".

The mother whose child had a disability and chronic illness, expanded the notion of grief,

talking about how her and her husband's acute grief at her son's death formed another layer upon the already present "grief during life" - and how throughout her child's life there was the constant spectre of death. Her husband agreed, describing the "intensive care, the chest infections, the specialists, the doctors; your kid is really sick and might not pull through but you think "no, he's done this before" – "you're well into the grieving". The mother talked about the *longing* that continues to be present over time – a longing even for the disability and all it entailed, the busyness, the adrenalin, the parental fatigue from years of care. She acknowledged that all these aspects of their child's life had given purpose to their own, all of which was lost at this death. She referenced a song by Tim Minchin and Missy Higgins called "I will carry you":

*If they would let me trade
I'd give a year for half a day
Just, curled up on the sofa with you.*

Group participants evoked the continuity of their grief, how it is a constant even for those who are many years down the track. But they did identify that how you express, respond to or manage your grief can evolve over time. The father who attended the group articulated it in this way: "Pain doesn't lessen; the way you deal with it does - out of necessity you get on with it". A mother described it in terms of the changing forms of grief over the years, with the acute experience as a "tsunami of grief", then "you learn to manage and live with grief – in the first year it's a fog- she's going to come back; in the second year, reality has hit; she's not coming back. As the years pass by you learn to manage the grief because you don't have any other choice".

Some described an ongoing effect manifesting in increased worry or vigilance about siblings

or other children, aware that catastrophe can happen and that children do pass away – an ongoing heightened fear. One needs to work out how to live with this fear, without “wrapping the other kids in cotton wool”. One mother spoke about her surviving child now having his license and a car, and the anxiety this brings. “I try to be calm, looking up the road to check he is okay. For two years he’s been with me in the car. I fear he doesn’t need me and fear losing him to idiots on the road”. Another mother agreed that this protective fear is very difficult when you are “terrified that something will happen to them”, but underlined the importance of letting surviving children “enjoy what life has to offer”. Another stated that her older son needed for her to “back off” – that he didn’t need her in the way that her other child had needed her. Other children “provide a lovely direction for me but I can’t expect them to fill the void”.

Others talked about the struggle to return to their work or other activities. One mother had stopped work to look after her child with a disability. She had attended a special needs group who were like “family”, with whom she could have “real and deep conversations”. Around other parents, conversations can feel mundane. “I can’t expect them to understand - it’s like I’m in a parallel universe and we are all existing side by side”. She feels it would be good for her to return to the workforce but is still recovering. Instead she launched into the home schooling challenge with her other kids during Covid, and attended to the garden. Other parents have found a sense of vocation that somehow has managed to keep them going despite intensity of grief. For instance, the mother who was devoted to teaching felt she had to keep doing this even when it was prob-

ably too early in her grieving. Another was a vet who loved helping people and their animals but after her son’s death cried all the way to work. At the time working with really



sick animals or euthanasia felt too difficult, but over time the growing feeling that she was doing something useful in the

world helped. Working gave her energy to put back into her family, and helped “in small doses”.

The bereaved parents in the group reflected upon the importance of working out how to best look after yourself as time goes on and grief continues to be there with you. This includes both doing things you need to do and allowing yourself time out to not do anything at all, or to attend to your grief as necessary. One mother noted that after nine years she is “not crying every day.” Some days “hit you harder than others” and she knows which days are the important ones to take off, for instance Mothers’ Day or birthdays. Parents highlighted the importance of knowing what you need and being able to act on this, including being able to ask people for what you need. One thing that changes for many parents following the death of a child is the capacity for patience with other parents and others in society. Parents expressed that discomfort can bring “stupid statements” from those around you in your extended family, work or social life. “You have to be more vocal about what you need- they are not programmed to understand”. Some parents de-

scribed how they struggled with comparisons between other people's losses and their own, and how angry this made them. One mother voiced how hard it was initially feeling it was "all about me" and being unable to bear to hear of other parents' losses, for instance of a much younger child, but that as time has moved on she has learnt that losing a child is as painful for any parent no matter what the circumstances.

Two mothers in the group described their anger at some parents' behaviour who they see as not adequately looking after or appreciating their kids. One stated "You want to scream at that parent- do you know how lucky you are? I would love to have all three kids driving me nuts, it would be heaven". However she tries not to voice this as she feels that other parents "don't deserve to get attacked when they're out at Coles". This mother pointed out that many people, even at times those closest to you, aren't equipped to help you through your grief. "They don't know how to be there for you and they say the wrong things". She described "I'm lucky I had three friends who get it, all mums. They are able to just sit in the really uncomfortable place. Without them I don't know how I would be functioning". There was some discussion about how crucial it is to find people who can "sit in uncomfortable places". Parents identified that over time you are able to "pick them" – the ones who can just be there with you, present to your loss and what you need, to be vulnerable with



you. "Being with them builds you up and doesn't deplete or exhaust you. Over time they are willing to sit in the space with me". A father in the group stated that many people don't know what to say- so "they say something stupid out of being uncomfortable". Sometimes though, support can come from unexpected places. He found that a local mechanic – a good-natured person whom he barely knew, was particularly supportive and caring. On the "flip side" one can have expectations of support from family or friends yet they can't do it. It is particularly helpful to find people who have known similar loss, who can bring comfort. "You find things out about people". An acquaintance came up to this father and confided that he had lost his son in a motorbike accident: "I'd just met him and I cried on his shoulder. It was just what I needed at the time. If we weren't grieving we would have never known that about him".

There was some discussion in the group about the importance of grief being able to be expressed in all its forms, and for the child to be remembered and acknowledged by others. One mother stated that she thought it was important for her surviving kids to see her grief "so they know it's real". This is a balancing act: "I don't want them swimming in my grief but I want them to see that it's normal to cry". Others spoke of how much it means when people mention their child, and how this provides relief amidst grief. One spoke of how she includes her daughter's name as an angel on cards she sends out and another mother thought she might also try this. Both agreed that over time you care less

about what other people think and more about what you need to get by.

Parents were asked whether they ever feel able to sit in other people's "messiness" or grief. One mother described that this was not possible early on but she finds increasingly, in the last year or two, she can be more comfortable "sitting in the silence. Even though their loss isn't the same as mine, they lost someone they love. Their world tipped upside down". Another more recently bereaved parent felt it was not possible yet but hoped "that will change over time- people feel that supporting someone is complicated but sometimes you don't have to say a word-sometimes there are no words".

Parents in the group articulated that for them grief does not pass and will not get smaller no matter how much other things in life change. "I will feel this on my death bed. I will still feel this grief – it's never going to pass". One parent described meeting an older man at church whose son "had passed sixty years earlier" and how he was still sad with grief. In many ways parents' grief sustains their memory of their child, who they continue to love as time goes on. "If you don't grieve it's like you've forgotten them- I'm happy to grieve as it's how I remember my child".

One mother stated "grief is the price you pay for love". "You loved them so much it hurts and even though they are not here, you still do." A parent asked her about how she had managed to get through the process of organ donation. She recalled the shockingly difficult decision that she and her husband had to

make at their daughter's death, to donate her organs at a time when they could barely comprehend their own loss, but chose in this moment to give a chance of life to other children. As the years since have progressed, a couple of the families whose child received a life-saving organ from her child have contacted her. It didn't feel enough - she really wanted to be able to "meet and cuddle them", to know that they understood the heartbreaking nature of this gift. However she spoke of one "beautifully written letter" which arrived from a recipient saying:

To my organ donor; every breath I take and every step I take is for you.

"I knew she understood".

**THANK YOU TO THE PARENTS WHO
ATTENDED THE JUNE GROUP AND
SHARED THEIR THOUGHTS ABOUT
LIVING WITH GRIEF, THEIR WISDOM
ABOUT WHAT CHANGES AND WHAT
STAYS THE SAME OVER TIME, AND
THEIR EXPERIENCE OF CONTINUING
LOVE AND REMEMBRANCE
OF THEIR CHILD.**



POEM FOR CHLOE -

Would your hair be any longer?
Would your eyes be just as blue?
Would you still be just as sweet?
As the young girl that we knew?

Would you be enjoying high school?
Would you have made new friends?
Would you still be playing netball?
Would you be into all the trends?

Would your team still be North Melbourne?
Your favourite animal - a giraffe?
Would you still love One Direction?
Would little things still make you laugh?

Do you have new friends in heaven?
Do they know how loved you are?
Have you been given your angel wings?
Are you still the brightest star?

This poem was written by Chloe's aunty

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 15th July 2021 at 7.30pm

Please join us to discuss the topic:

“Ideals and Reality; Juggling the mismatch “

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



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Social Work Department, RCH

