

Living Forward

A newsletter for bereaved families

Summer 2020



New beginnings for 2020

A very warm welcome to all of the families, friends, community partners and colleagues who are part of the ever-increasing readership of Living Forward. Firstly, we'd like to pause and acknowledge the grieving families who are receiving this newsletter for the first time. We are deeply saddened by the loss which brings you to this community, as we know this collective is one you would never wish to enter. It is our hope that you will find comfort and companionship from others who walk beside you in grief, and support to navigate a way forward.

As we transition into the new year, we are excited to announce the next edition of Living Forward will be our first electronic newsletter. Moving to a new, contemporary

format will allow us to provide a more responsive way of sharing information and resources with our growing community. This step forward will enable us to deliver better and more timely access to support, resources and services. As this will be our final print edition, we encourage you to stay in touch by updating your email address with CHQ Bereavement Services by emailing your name to bereavement.ppcs@health.qld.gov.au with 'Living Forward' in the subject line.

Continuing with the theme of transition, we are pleased to bring you an overview of the actions and projects CHQ Bereavement Services has in its sights for 2020. Turn to page two to learn more about the activities we have lined-up for the year ahead. In another special

feature this edition, we share some reflections from the Children's Health Queensland 2019 Annual Remembrance Ceremony, and we take time to remember some highlights from the inaugural Good Grief, This Hurts symposium.

Finally, we welcome your suggestions for items of interest, services, supports, books or blogs which you feel might be of interest to others within this community, so please share your thoughts with us at any time. Know too, the Bereavement Service is here for you in this new year. If ever there is a time you, or those caring for you need support, please reach out.

With warmest wishes,
Alyson, Leigh and Sophie



The year ahead

In 2019, we worked in partnership with an energetic and deeply compassionate group of bereaved parents to develop the CHQ Bereavement Services Action Plan. The Action Plan is broad and seeks to respond to the unique needs of bereaved families throughout Queensland and Northern New South Wales. While we acknowledge many families find solace in the comfort of family and friends, others find becoming a bereaved parent can be lonely and isolating.

The Action Plan, released in November 2019, outlines a new vision statement; No bereaved family member who needs and wants support is ever left alone.

This year, we will commence an ambitious project to develop a Parent Mentor Program. The program will invite parents who have experienced grief to undertake training to mentor and support newly bereaved family members. We understand mentorship can be very meaningful for parents and create a sense of community for newly bereaved families. The project will be a collaboration between Children's Health Queensland and bereavement services in tertiary paediatric hospitals across New South Wales, Victoria and South Australia.

We will also be working towards building a new CHQ Bereavement Services website that will become a central hub of information, resources, services and events. The site is intended to make it quicker and easier for bereaved families and professional caregivers to find quality information at this difficult and confusing time of life.

Importantly, these projects will be carefully guided by the new Family Advisory Group that will sit alongside CHQ Bereavement Services. Over time we will invite new representation to this committee to ensure ongoing diversity in the group.

Join us online! Register your email address

The Bereavement Service is excited to confirm the next edition of Living Forward will be an electronic newsletter that will be delivered via email straight to your inbox. This change will help us continue to grow with our community by allowing us to deliver better, and more timely support, services and resources. To stay connected, please register your email address by emailing your name to bereavement.ppcs@health.qld.gov.au with Living Forward in the subject line.



We want to hear from you

In November we welcomed Norah Elvidge to our growing service. Norah is undertaking a Vacation Research Experience Program (VRES) through the Queensland University of Technology and is working with us to evaluate the current bereavement service. We will be extending invitations to all bereaved family members who receive Living Forward and we encourage you to consider participating in the service evaluation. This is your opportunity to share with us how we can best meet your needs now and into the future. Please look out for updates in the coming weeks.



CHQ Bereavement Service Family Advisory Group:
(L-R) Dayna, Kerry, Rachel, Louisa, Chris, Sharni,
Suzanne, Pip, Ewan & Brett.

Children's Health Queensland Annual Remembrance Ceremony

Each year, the Children's Health Queensland Annual Remembrance Ceremony brings together parents, siblings, carers, friends, grandparents and extended family to remember the loss of loved ones. On Saturday, 26 October, more than 250 people gathered at Somerville House to participate in symbolic rituals and activities to honour the children in our community who are no longer physically present. An integral part of this ceremony is the family members who reflect on their experience of love and loss. We're sincerely grateful to the families who generously shared their stories with us at the 2019 ceremony, and we would like to take this opportunity to share some of their reflections with you in the hope that you will draw some comfort from their heartfelt accounts.

Light after darkness

Annie Love - loving mother to Nicholas

'Nicholas was the portal to my greatest lesson in life; when we are going through darkness, there is always a light on the other side, even if the landscape looks different to how we thought it should look.'

'In March 2016, we celebrated Nicholas' fourth birthday, later that night he developed a fever, and over the following few weeks he never seemed 100 per cent again. One evening, we were concerned about Nicholas' breathing and decided to take him to the children's hospital. At midnight, I rang Ben (my husband) to explain that Nicholas was being admitted for a suspected throat infection. But things declined very quickly, and within a matter of hours, Nicholas was moved to ICU - battling a number of life-threatening conditions.'

'Over the next three weeks, we rode the rollercoaster that is life with a child in ICU. We had many difficult conversations with doctors. We celebrated days when things seemed to be improving, endured days when nothing changed, and we had agonising days when new battles arose. We prayed, we begged, we used dark humour to get us through, we hoped, we laughed, and we cried. And there was not a moment, not even one, where we contemplated that we wouldn't be able to take our baby boy home at some stage.'

'And yet, on 2 May 2016, our beautiful boy died in the wee hours of the morning with us in the bed beside him, and our final journey home from the hospital was without Nicholas. The phones that we'd had on 24/7 for medical updates were silent. Nothing could prepare us for this cavernous loss. There's no manual for living without your child.'

'When we arrived home from the hospital, I would have been quite happy to lock ourselves in the house and never see anyone else ever again. It felt so cruel that the world continued to turn without Nicholas in it.'

'In a matter of days after Nicholas died, we needed to choose a burial place, write a eulogy, coordinate a funeral service, and



Annie and Ben Love, parents of Nicholas

make plans. And amidst all those decisions, we also had to parent six and eight-year-old boys who'd just lost their little brother. They needed us, but we didn't have a lot left to give.

'My brain swirled with all those thoughts around what I could have done differently to keep Nicholas alive, how we could have saved him. And the bloody flowers kept arriving on the doorstep. I didn't want flowers, I just wanted my baby boy back in my arms.'

'Living with grief is not easy, but for me it has become easier to live with over time. Day by day, I edge towards working out who I am without Nicholas physically present in our lives and I step more into this new version of me. I work around the space he has left in our lives, trying to keep our connection to Nicholas whilst also having new adventures and experiences without him.'

'Finding the grace to accept Nicholas' death is a work in progress, but over time, we have come to understand that to truly honour him, we need to live our best lives too.'

A shift in grief

Ben Love - loving father to Nicholas

'The early days without Nicholas were brutal. They would start with those few blissful seconds of half-sleep oblivion before consciousness would dawn and bring with it the crushing reality of what had happened. Each day brought a pain so raw that I was numb.

'For the first year I clung to my grief as tightly as I'd clung to Nicholas in his final moments. I had been powerless to hold on to him in life; I was determined not to let go of him in death. Every Tuesday without fail I would eat my lunch with him, sitting on the grass beside his grave, telling him how much I missed him. I would lie beside him and cry; sometimes quiet tears of reminiscence, sometimes great gasping sobs that left me drained and exhausted, after which I would curl up and nap beside him before returning to work.

'Nicholas in life had changed me. He had helped me to discover a better version of myself that I didn't know could exist. A version of myself that I liked far better than the one I had known previously. When we lost Nicholas, I also felt like I had lost that better me. He had shown me what life could be, what I could

be. But then he was gone. I had broken the cardinal rule of parenting – I had failed to keep my child alive. I had lost him, and in the process, I had lost myself.

'It was almost exactly one year after his death that things started to shift. My thoughts of Nicholas were slowly transforming from pain, loss and guilt to happier memories that would bring a quiet smile to my face. I was rediscovering the pride I had felt in my boy and the inspirational way he had lived every moment of his four short years. My visits to his grave grew less frequent as my connection to him shifted from his body in the ground to the memories in my heart.

'In his four short years, Nicholas was our teacher, our inspiration and our guide. He showed us how life could be lived, full of joy and love. His life, and his death, will always be a part of our story - but we can choose what we do with that story. Our boy is gone. He is not coming back. But we choose to honour his life and his legacy by embracing the lessons he shared with us. We make the choice to rediscover joy in the world. To live with love and an open heart. It is not always easy. Sometimes we fail. But this is the choice we make.'

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This is a thing many people outside your grief cannot understand: that you have not simply lost one person, at one point in time. You have lost their presence in every aspect of your life. Your future has changed as well as your 'now'.

Megan Devine, *Refuge in Grief*

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Finding happiness in heartache

Chelsea Luders - loving sister to Mitchell

'In August 2011, Mitchell, just nine at the time, was diagnosed with Neuroblastoma - which is a fancy term for one of the many forms of childhood cancer. Four years later, at the age of thirteen, despite a fierce battle, Mitchell passed away. Losing Mitchell has been the most emotionally demanding and confusing time in my life.'

'In the days after his passing, Mitchell was all anybody talked about, I was smothered by people expressing their condolences. I knew they were trying to be helpful, but they didn't know Mitchell like I did, and I found it hard to believe they knew how I felt. People I'd never even seen before tried to tell me that Mitchell was in a better place now, but that was quite unbelievable too. Nevertheless, I accepted the awkward hugs and the random flowers because I knew they came from a place of love and care.'

'At the funeral, we celebrated Mitchell's short life with photos, songs and stories, and then it felt like everyone just went home, and back to their normal life. Like they'd simply pressed pause for a couple days to grieve and to process, and now everything was fine, and so were they. But for me and my family, it felt like there was nothing to go back to. It was obvious how much we were all hurting and we all tip-toed around each other to avoid making matters worse, but I don't think that was even possible.'

'I struggled to cope with the onslaught of emotions. Of course, I was sad, but I was also angry. I was so mad that Mitchell had endured so many difficulties in his life which he fought so

graciously, only for it to feel like none of that had payed-off. Looking back, I think sometimes it was just easier to be angry because the alternatives were just so tiring. When I was upset, I felt like I was wandering aimlessly. I've realised, a lot of my tears were coming from a place of anxiety and fear. They came from the fear of having to grow up without Mitchell, and the fear that this feeling of being lost would never stop.'

'Sadness also came from the fear that I would soon forget the sound of his voice, his laugh, or even worse - that others would forget about him. I feared the 'other side' of grief, and all the things it implied - the idea that someday I would no longer miss Mitchell. But now I've learnt that there isn't necessarily another side. There's no 'pushing through' this, but rather there's adaption where we learn to take the good days with the bad and live alongside grief.'

'I have no doubt that, if given the chance, Mitchell would have changed the world. Without him, everything is so different now. But as much as losing Mitchell has been tiring, confusing and miserable - I now feel as though I have this extraordinary power. When you can't imagine going on any further, but your heart keeps beating, there is strength in that. And with this strength, this hope, I've learned that there's joy to be found in living a life that Mitchell would be proud of. I've found that I can honour him by finding happiness in the heartache. By living freely and bravely even when it's hard, and by spreading every ounce of love I have. And so, in this context, Mitchell did change the world; he changed the world for me.'

Supporting children through grief

On 21 October, a broad group of caregivers, teachers, guidance counsellors, health professionals, counsellors, psychologists, and youth-focused organisations came together with family and friends of children touched by the loss of a loved one for the inaugural Good Grief, This Hurts symposium. The event was held in response to calls from our community for assistance to better support children and young people manage the impact of death on their lives.

With the support of a diverse range of stakeholders, including bereaved parents, we crafted an innovative program aimed to address the vulnerability associated with supporting a bereaved child or young person. The event explored themes of heart, head and hand with the help of special guest speakers, music, poetry and imagery.

We would like to thank and honour each of the caregivers, family members, friends and professionals who shared their knowledge and personal experiences with us, including:

- Elham Day, family support coordinator of Hummingbird House who opened the event by inviting participants to explore their personal relationship with grief
- Anne Finigan (bereaved mother of Josh), Amy Finigan (bereaved sister of Josh), Dalya Shaw (bereaved mother of Ben and supporter of Ben's friendship group), Lachlan McKenzie (bereaved sibling to Chloe) and Suzanne Beames (bereaved daughter and bereaved mother of John) who generously shared their experience as a bereaved sibling or carer of a bereaved young person

- our panel of professional caregivers who discussed actively supporting grieving children and young people, and
- music therapist, Dr Jeanette Kennelly, who demonstrated how music can be integrated into our lives as a source of wellbeing.

Following the positive feedback from event participants, we will move forward to include Good Grief, This Hurts as an ongoing, annual event in the CHQ Bereavement Services calendar. We look forward to sharing more news with you about this event later in the year. If you would like to receive event updates for 2020, please contact CHQ_bereavement@health.qld.gov.au.



Anne and Amy Finigan



Elham Day, Family Support Coordinator, Hummingbird house

Teen workshops

If you're looking for further grief support for teenagers, counsellor Karen Lang hosts teen and young adult grief workshops specifically tailored for young people aged 14 to 19. The workshops are held in a safe and calm environment, and designed to assist participants to gain a deeper understanding of their feelings.

During the workshops, participants learn strategies and understanding of loss and grief through art therapy, group discussion and activities. The sessions aim to build new pathways of understanding and provide guidance to discover inner courage and strength.

If you would like more information, please phone 0413 237 604.

Keeping Connected. The Bereavement Support Program based at Queensland Children's Hospital offers telephone support and counselling Monday to Friday from 8.30am to 5pm. We acknowledge there are no timeframes for mourning the loss of a child – we continue to be available for you and your family – ph 1800 080 316 e bereavement.ppcs@health.qld.gov.au

Support services

Australian Counselling Association

Grief and trauma counselling.
 t 1300 784 333 w theaca.net.au

Australian child and adolescent trauma, loss and grief network

Grief and trauma resources.
 w earlytraumagrieff.anu.edu.au/grief-and-loss

Australian Centre for Grief and Bereavement

w grief.org.au
 Grief and bereavement education and resources.

Australian Psychological Society

Psychologist directory.
 t 1800 333 497 w psychology.org.au
 e contactus@psychology.org.au

Anglicare South East Queensland

Anglican Church's family and relationship counselling service.
 t 1300 114 397 w anglicaresq.org.au or
betterrelationships.org.au

Aboriginal and Torres Straight Islander Corporation Counselling Service

Counselling service for Aboriginal and Torres Strait Islander community.
 a 57 Southgate Ave, Cannon Hill Q 4170
 t 07 3899 5041 w gallangplace.org.au

Canteen

Specialist services for people aged 12-25 dealing with a family member's cancer or the death of a parent or sibling.
 t 1800 835 932 w canteen.org.au/getsupport

Cancer Council Queensland

Free telephone counselling service for people impacted by cancer and those close to them.
 t 13 11 20 w cancerqld.org.au

Centacare

The social services arm of the Catholic Church, offering counselling services.
 t Cannon Hill 07 3399 5671
 Fortitude Valley 07 3251 5000
 Clear Island Waters/Beenleigh 07 5527 7211
 Maroochydore 07 5430 9300
 Kingaroy 07 4162 5439
 w centacarebrisbane.net.au (Bris area)
centacarenq.org.au (North Qld)
centacare.net (Central Qld)

Coronial Family Services

Counselling for relatives and close friends of people whose deaths are being or have been investigated by a coroner.
 t 07 3096 2794 or 1800 449 171
 e fss_counsellors@health.qld.gov.au

Compassionate Friends

Grief and trauma support following the death of a child.
 a 505 Bowen Terrace, New Farm Q 4005
 t 1300 064 068 (24Hr National Helpline)
 w compassionatefriendsqld.org.au
 e admin@tcfqld.org.au

Community Health Queensland

Resources and links to organisations which offer free counselling services with a social worker or psychologist.
 t 13 HEALTH (13 43 25 84)
 w qld.gov.au/health/support/loss

Gateway Counselling

A Gateway Baptist Church service that offers a variety of counselling services for families.
 t 07 3291 5963 w gatewaybaptist.com.au
 e gcwc@gatewaybaptist.com.au

Karen Lang Courage Workshops

Monthly courage workshops to support parents who face the death of a child.
 t 0413 237 604 w karenlangauthor.com
 e naaron2@hotmail.com

Kids Helpline

A free and confidential counselling service for young Australians aged 5-25.
 t 1800 55 1800
 w kidshelp.com.au or kidshelpline.com.au/
teens/get-help/webchat-counselling
 e counsellor@kidshelp.com.au

Leukaemia Foundation of Queensland

Offers grief support services and resources to Queenslanders who have lost someone to a blood disorder like leukaemia, lymphoma or myeloma.
 t 1800 620 420 or 07 3055 8233
 w leukaemia.org.au

Lifeline

Offers 24-hour support and suicide prevention services via phone and online crisis support chat.
 t 13 11 14 w lifeline.org.au

MensLine Australia

Provides resources and support for men with family and relationship concerns via phone, online, video counselling and online forums.
 t 1300 789 978 w mensline.org.au

Paradise Kids

Offers support programs and counselling for children affected by grief, loss and trauma. Paradise Kids offer a variety of face-to-face support services on the Gold Coast.
 a 88 Allied Dr, Arundel, Gold Coast Q 4214
 t 07 5574 6853 w paradisekids.org.au
 e services@paradisekids.org.au

Parentline

A confidential telephone counselling service which aims to support parents and carers of children between 8am-10pm, seven days.
 t 1300 30 1300 w parentline.com.au

Pillars of Strength

Supports dads who have lost their child in infancy, through stillbirth or in the neonatal intensive care unit.
 a www.pillarsofstrength.com.au
 e info@pillarsofstrength.com.au

Precious Wings

Provides the gift of a memory box to bring comfort to grieving families who have lost a baby or child of any age or gestation.
 w preciouswings.org
 e info@preciouswings.org

Redkite

Free support services for bereaved families of a child who has died of cancer.
 t 1800 REDKITE (1800 733 548)
 w redkite.org.au/bereavement-support
 e support@redkite.org.au

Red Nose (formerly Sids and Kids)

Provides free resources and support services to those affected by the sudden and unexpected death of a baby or child up to six years of age.
 t 1300 998 698 or 1300 308 307 (24-hour)
 w rednose.com.au

Relationships Australia

Provides counselling to help enhance and support relationships and assist with grief.
 t 1300 364 277 w raq.org.au

Sands Queensland

Provides free support, information, education and advocacy for parents and families of babies who have died during pregnancy, at birth or soon after.
 t 1300 072 637

Scarlett May Foundation

Supports families with critically ill children in hospital by providing meals during hospital stays, on-going counselling and funding for parents to purchase keepsakes of their passed child.
 t 0411 088 748 w scarlettmayfoundation.org.au
 e info@scarlettmayfoundation.org.au

Skattle

Supports children, teenagers and their families experiencing difficulties arising from events such as illness, grief and loss and separation.
 a 44 Newdegate St, Greenslopes Q 4102
 t 07 3847 9943 w skattle.org.au

Living Forward is produced by Children's Health Queensland Bereavement Support Program. If you would like to provide feedback, share any news with us, or no longer wish to receive this newsletter, please email bereavement.ppcs@health.qld.gov.au