

# Living Forward

A newsletter for bereaved families

Winter 2019

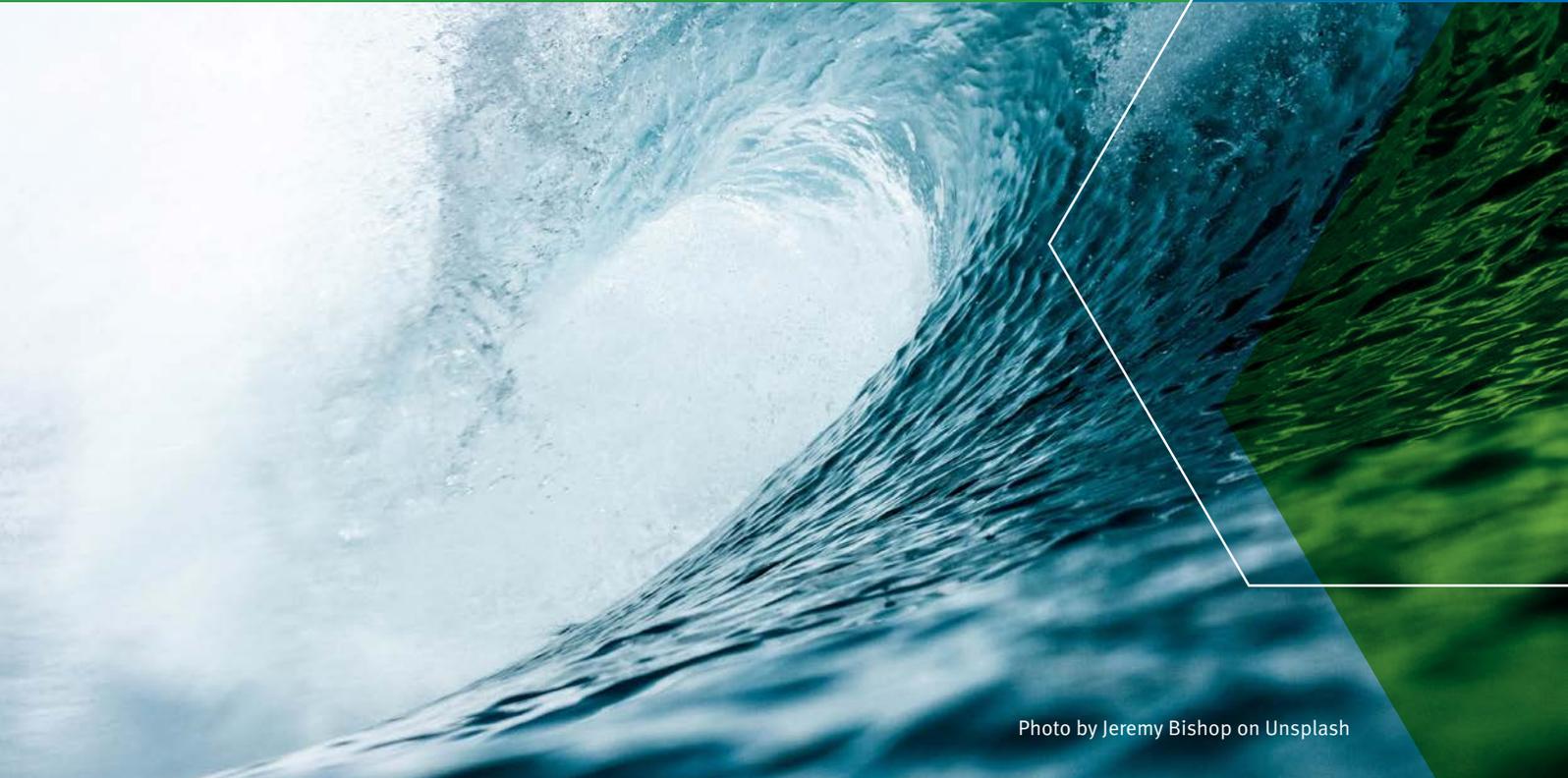


Photo by Jeremy Bishop on Unsplash

## When words are not enough... alternate ways to describe the experience of grief

Metaphors are more than figures of speech; they can offer structure to the way we perceive, think about and also what we do, in our reality. Those who are grieving the loss of a loved one are forced to construct a new reality and the challenge exists in how to find the words to capture and reflect back this utterly unknown, unfamiliar space. We share these metaphoric descriptions of grief, which offer another viewpoint.

In the 1980s, Dr Richard Wilson, a paediatrician who was working alongside parents following the unexpected death of their child to SIDS, articulated a model around the 'Whirlpool of Grief' (Figure 1) metaphor. This understanding suggests an unsuspecting oarsman travelling along 'the river of life' representing the known-life before bereavement. The 'waterfall of bereavement' captures the shocking experience

of losing your child, where you are at the mercy of powerful and overwhelming emotions as you career down the waterfall.

At the bottom of the waterfall is the whirlpool and this illustrates the emotional upheaval and disorganisation that follows the death of a child.

The whirlpool spins you round and around and you can do little except be carried along where the tumultuous waters take you. Sometimes, you will unexpectedly hit submerged rocks or encounter river debris and these obstacles may cause stronger responses and again, you can do little to control your trajectory. Occasionally, you might find a little respite in shallow, calmer waters. Yet, on your travels the reality of your unexpected course begins to feel more familiar. There will continue to be impediments along the river and these will trigger painful experiences and overwhelming emotions.

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## In this edition

Welcome to all families and service providers who collectively receive *Living Forward*. As the years progress, our community continues to grow. We begin each edition by acknowledging those families who may be receiving this newsletter for the first time. While we warmly welcome you, we also acknowledge that this may be a community you did not anticipate ever joining. We hope you find a little comfort, companionship and solidarity in these pages.

Grief can feel like such a foreign experience and knowing how to navigate your way through intense feelings and emotions can be difficult. A regular feature of *Living Forward* is the sharing of frameworks that may normalise or provide guidance for you and those around you. This season, we share metaphors for understanding loss. Grief is never a linear experience. We hope that in reading this article, you find some sense of hope amidst the whirlpool and the waves that may currently engulf you. Please know these will eventually recede, allowing space to pause and rest.

We believe it takes a village to care for those whose child has died. In our winter edition of *Living Forward* we share a range of community engagement activities that highlight our commitment to building confidence in our community when it comes to knowing how to walk alongside a bereaved family member, friend, child or young person. Our first stops have been Rockhampton and Cairns where we came together with parents and service providers to build confidence and strengthen networks in this space.

Many parents we meet struggle to articulate grief. The physiological and neurological impact of such suffering can impact one's ability to express their feelings as they may have in the past. Music has long been an adjunct to suffering and on page 5, we share some thoughts about creating a 'playlist for grief'. We invite you to consider what is on your playlist and how this may have provided solace in times of distress.

When we next reach out to you, spring will be unfolding and with its arrival, the anticipation of warmth. As always, please make contact with the Bereavement Service if there is ever a time you need support.

With warmest wishes,  
Alyson and Sophie

# When words are not enough...

For some, a sandy bank may present another obstacle, where those grieving might remain 'washed up' and disorganised for a longer period of time. It might be that you've been unable to grieve, as the task of navigating the rapids has been wholly consuming, while others are overwhelmed by their emotion and struggle with daily tasks.

Gradually, at different rates of flow, the 'river of life' leads to calmer waters.

Figure 1: Whirlpool of Grief



Another analogy on grief is 'grief as a shipwreck'. The following piece has featured on a host of sites, however the author is unknown:

*"As for grief, you'll find it comes in waves. When the ship is first wrecked, you're drowning, with wreckage all around you. Everything floating around you reminds you of the beauty and the magnificence of the ship*

*that was, and is no more. And all you can do is float. You find some piece of the wreckage and you hang on for a while. Maybe it's some physical thing. Maybe it's a happy memory or a photograph. Maybe it's a person who is also floating. For a while, all you can do is float. Stay alive.*

*In the beginning, the waves are 100 feet tall and crash over you without mercy. They come 10 seconds apart and don't even give you time to catch your breath. All you can do is hang on and float. After a while, maybe months, maybe longer, you'll find the waves are still 100 feet tall, but they come further apart. When they come, they still crash all over you and wipe you out. But in between, you can breathe, you can function. You never know what's going to trigger the grief. It might be a picture; a street intersection; a smell. It can be just about anything... and the wave comes crashing. But in between waves, there is life.*

*Somewhere down the line, and it's different for everybody, you find that the waves are only 80 feet tall. Or 50 feet tall. And while they still come, they come further apart. You can see them coming. An anniversary, a birthday, or Christmas... You can see it coming, for the most part, and prepare yourself. And when it washes over you, you know that somehow you will, again, come out the other side. Soaking wet, spluttering, still hanging on to some tiny piece of the wreckage, but you'll come out...*

*The waves never stop coming, and somehow you don't really want them to. But you learn that you'll survive them. And other waves will come. And you'll survive them too..."*

We imagine you will find your own way to describe your experience of grief after the loss of a child, thereby telling your own story.

Article sourced from: [www.whatsyourgrief.com](http://www.whatsyourgrief.com)

# Sharing your experience to help others

In the autumn edition of *Living Forward*, you may recall our update regarding the appointment of the new Children's Health Queensland Bereavement Coordinator, Leigh Donovan. This role complements the existing Bereavement Service (Alyson Gundry and Sophie Weeks) that sits within the Paediatric Palliative Care Service and will extend care to all bereaved families whose child was cared for at Queensland Children's Hospital.

The first step in working towards development of a hospital-wide response to the care of bereaved families is listening to the experiences and needs of families themselves. We want to ensure parents and other family members are involved in all

aspects of program development now and into the future.

Are you a bereaved parent who would like to make a difference in the life of other bereaved families?

Do you have some important messages to share with professionals through a formal education program?

Would you like to be involved in the development of a parent advisory group to support the CHQ Bereavement Service?

If you answered yes to any of these questions, we invite you to email the Program Coordinator, Leigh Donovan: [CHQ\\_Bereavement@health.qld.gov.au](mailto:CHQ_Bereavement@health.qld.gov.au). Please include your full name, phone number and the best day and time for us to reach out to you.

“

*We run from grief because loss scares us, yet our hearts reach toward grief because the broken parts want to mend.*

Brene Brown

”

## Save the date: Children's Health Queensland 2019 annual remembrance ceremony

This year's Children's Health Queensland Remembrance Ceremony will be hosted on the morning of Saturday, 26 October 2019 at the Honour Room function space, Foundation Building, Somerville House School, which is located across the road from the Queensland Children's Hospital.

Each year a Remembrance Ceremony Organising Committee, made up of clinical and non-clinical staff from the Queensland Children's Hospital, QCH School and the Children's Hospital Foundation forge links with community service partners (such as Heartkids, Hummingbird House and Precious Wings) to plan a ceremony allowing families to draw support from many quarters of the community.

**Planning for this important annual event continues and if you and your family wish to be involved, please contact us.**

Please be advised that invitations will be posted towards the end of September 2019, so if you plan on attending and have not received an invitation by early October, please make contact and we will forward the details. When the invitations have been mailed out, there will also be a notice on the Children's Health Queensland Facebook page, which will serve as a prompt if your family's invitation doesn't arrive by post. Finally, if your contact details have recently changed, please make contact at [bereavement.ppcs@health.qld.gov.au](mailto:bereavement.ppcs@health.qld.gov.au) and we will update the Remembrance Ceremony invitation list.



# From the ashes

We always welcome contributions from our readers. Over the years, countless pages of this newsletter have been filled with bereaved families generously sharing stories of interest and this edition is no exception.

Many of you will know Nick Cave, front-man for the band, Nick Cave and the Bad Seeds, and you might also be aware that he is a bereaved dad following the tragic death of his 15-year-old

son in 2015. In September 2018, Nick Cave launched *The Red Hand Files*, a website where he solicits questions from his broad fan-base and then responds with vulnerability, humour and compassion.

A regular reader of *Living Forward* (and perhaps a Nick Cave fan) passed on an extract from *The Red Hand Files* where Nick Cave discusses watching his wife, Susie, grieving their son Arthur's death. Included here is an abridged version of his reflections.

Dear Vivian,

Susie is sitting across the kitchen table from me, humming to herself and knitting what looks like a scarf. I have just read her your very sweet message...

In *One More Time With Feeling*, (a 2016 documentary about Nick Cave), we see an interview with a woman who is new in her grief. I don't think I could ever watch that piece of footage of Susie again. It was the very hardest part – to see, day by day, the uncontainable and merciless dimensions of grief. It is the very reason I am so careful when I reply on *The Red Hand Files* to people who have lost someone, because I have seen the tenuous hold that a grieving mother has on life itself. I have seen the paralysis and the terrible retreat from the world. I have seen life lived in a darkened room, essentially a tomb, crumpled around a memory, as if to be dead herself somehow brought her closer to the spirit of her departed child. I learned the appalling meaning of the words 'inconsolable' and 'helpless' – and I never knew a person could cry for so long.

But I have also seen a woman ultimately step from that room, changed – defiant and scoured clean by grief; a woman with a mutinous and ferocious grace, now more open, daring and creative than ever; a woman who has simply defied the cosmic odds and bloomed.

And I think that is what Susie and I want to say to those deep in grief, to the inconsolable. We want to say that, in spite of ourselves, life moves on. That in time, we learn to absorb our loss, as a form of armouring, and that it can become our strength. That the very thing we thought would destroy us, now becomes a fierce source of creative power, as if our departed are breathing an essential energy through us, drawn from a wellspring deep within the trauma itself. We want to say that allowing this process of renewal to occur is the greatest gift we can give to those who have left us. We become the living vessels that carry their spirits, out of that dark and shuttered place, and release them into the heavens.

Finally, we want to say that even though there are still the deep and sudden weeps – the flash floods – they don't assert the same hold on us anymore, for we know they pass, as do all things.

So, Vivian, to answer your question, "how is Susie doing?" Susie is doing okay. I watch her now, across from me, humming to herself and knitting a scarf and I am awed.

Love, Nick

(Sourced from [www.theredhandfiles.com](http://www.theredhandfiles.com))



Photo by Daiga Ellaby on Unsplash

# Music: Do you have a playlist for your grief?

Photo by Melanie Pongratz on Unsplash

When grieving, often what is needed is care to be offered from a variety of sources. It might be a phone call from the right person at the right time or an unexpected and thoughtful message from a friend giving comfort. These small gestures may remind you that someone knows, remembers and is reaching out to tell you so. Much solace can be provided when others are prepared to 'turn up' and sit alongside you in your grief.

But sometimes, you may not feel able to wait for this to happen, and you will need to tap into your own sources of comfort. Many have shared that they have found their way to a few songs that have helped them when greiving; the soundtrack to their experience of loss.

Perhaps, a certain song may contain a phrase that reflects for you the very emotion that needed to be expressed, and this may be particularly so when words alone seem inadequate. Or the lyrics may offer a differing viewpoint about how to endure loss or provide a trigger for you to remember a small moment that was almost lost. The melody, the vocals and the associated memories can evoke strong emotions which might produce comfort in the midst of sorrow. Or the music might give space for the complexity of emotions being felt to be unleashed and fully expressed.

Another added benefit is that music doesn't disappear. It endures and today, it is even more accessible than ever. Like music, the memories of a loved one linger. Sometimes

songs will stick in your heard, even when we don't especially want them to, becoming what's called an 'earworm', playing over and over.

Memories can also do this, sometimes bombarding you when you don't want them to. Even these unwelcome recollections demonstrate that your connection to your loved one continues.

We'd be interested to hear which songs might feature on your playlist? Please make contact and let us know.

“  
*Music speaks to my soul  
In a way that mere words cannot  
Music speaks of my pain  
Expresses my joy  
Shares my memories  
Through music  
the emotions of grief  
Are shared  
In beautiful rhythms  
and soothing words.*

Tanya Lord, *Music speak to the soul* ”

From [thegriefftoolbox.com/artwork/music-speaks-soul](http://thegriefftoolbox.com/artwork/music-speaks-soul)



# Community bereavement events

## Community capacity building – building strong networks around families whose child has died

Children’s Health Queensland Bereavement Services and the Quality of Care Collaborative Australia (QuoCCA) have embarked on a series of community bereavement events throughout regional Queensland. The mission behind these events is to gather bereaved parents, formal and informal caregivers and service providers in conversation around the following themes:

- hearing the experience of bereaved families
- mapping community bereavement care networks
- working with the community to create an action plan moving forward
- enhancing networks and connections.

### Why community capacity building?

Bereaved families whose children were cared for through Queensland Children’s Hospital are scattered far and wide across Queensland. Many families describe significant social isolation following the death of their child. Members of their community often do not know what to do or how to care for a bereaved family. These capacity-building events aim to reduce isolation for families, build confidence in the community and ignite strong networks of care and resources.

To date, we have held two events in Rockhampton and Cairns. We are grateful for the support of our community champions in each region who worked with us in planning and promoting the events. Each event attracted a diverse range of

stakeholders including bereaved parents and friends, hospital staff, representatives from Education Queensland and local schools, non-government organisations, funeral providers and parent service providers.

The event begins with a parent sharing the story of their child’s end of life and their family’s bereavement. Throughout the story, the parent identifies the ‘roses’ – what went well, ‘the buds’ – what could have been improved, and ‘the thorns’ – those things that were difficult and where significant change is required. We then invite all participants to join in the conversation working collectively to identify how as a community, we can work together to effect positive change. The learnings from each event are shared back with the community and will guide our collective response to enhancing how we respond to the care of families whose child has died.

Rich learnings so far:

- Caring for the bereaved ‘takes a village’.
- Bereavement care is everyone’s business. We all need to learn how to ‘show up’ with compassion for those whose child has died.
- We have been reminded how important it is to name and remember the child who has died and continue to do this for the years ahead.
- We cannot fix the pain of loss but as a community, we can learn to walk alongside bereaved families in a meaningful way.

We look forward to planning our next regional event in the coming months and will keep you updated via *Living Forward*.

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# Community bereavement events

## Good Grief, This Hurts symposium

We are excited to announce that registrations are now open for the Good Grief, This Hurts symposium, which will take place on Monday, 21 October 2019. This inaugural event responds to the call from our community to learn how we can build confidence in knowing how to support children and young people to manage the impact of death on their lives. With the support of a diverse range of stakeholders, including bereaved parents themselves, we are creating an innovative program that will address the vulnerability we all feel in supporting a bereaved child or young person and demonstrate creativity in how we can do

this. We invite anyone in the community supporting a child impacted by death to attend. This includes family caregivers, teachers and guidance counsellors, health professionals, counsellors and psychologists, youth-focused organisations. The day will be interspersed with opportunities for self-reflection and self-care through music, photography, conversation and creativity.

The Good Grief, This Hurts symposium will take place in the Honour Room, Foundation Building, Somerville House. To register and for more information, visit the event page <http://tix.yt/goodgriefthishurts>

Please see the attached event flyer for further details.

## Good Life, Good Death Expo

The Good Life, Good Death expo will take place on **Sunday, 1 December 2019** and offers relevant, up-to-date information about palliative care to the community. The aim of this expo is to normalise dying, reduce peoples' fears and ensure that no one ever feels like a burden to others. The expo is an initiative of Palliative Care Queensland. For more information, visit [www.goodlifegooddeathexpo.org.au](http://www.goodlifegooddeathexpo.org.au)



**GOOD LIFE GOOD DEATH EXPO**  
NO TABOOS: EMBRACING ALL OF LIFE  
[www.goodlifegooddeathexpo.org.au](http://www.goodlifegooddeathexpo.org.au)

**EVERYONE IS INVITED**

- FREE Entry
- FREE Barrista Coffee
- FREE Showbag
- FREE Face Painting
- FREE Photobooth
- FREE Information
- FREE Expert Seminars
- FREE Door Prize

A **FREE** community expo to start conversations, learn, connect, nurture compassionate communities and plan!

Date: Sunday 1 December 2019  
Time: 10am-3pm  
Location: Brisbane Convention and Exhibition Centre

Register before you attend and go in the draw to win an ipad  
[goodlifegooddeathexpo.org.au](http://goodlifegooddeathexpo.org.au)

Open conversations about:  
Life | Loss | Love | Ageing | Legacy | Disability | Values | Dying | Compassion | Choices | Death | Dignity | Grief

A free community event organised by Queensland Compassionate Communities - the community arm of Palliative Care Queensland

## CARTOGRAPHY of GRIEF



“

*Grief is visceral, not reasonable: The howling at the centre of grief is raw and real. It is love in it's most wild form.*

Megan Devine, [www.refugeingrief.com](http://www.refugeingrief.com)

”

**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](mailto:bereavement.ppcs@health.qld.gov.au)

# Support services

## Australian Counselling Association

Grief and trauma counselling.  
 t 1300 784 333 w [theaca.net.au](http://theaca.net.au)

## Australian child and adolescent trauma, loss and grief network

Grief and trauma resources.  
 w [earlytraumagriev.anu.edu.au/grief-and-loss](http://earlytraumagriev.anu.edu.au/grief-and-loss)

## Australian Centre for Grief and Bereavement

w [grief.org.au](http://grief.org.au)  
 Grief and bereavement education and resources.

## Australian Psychological Society

Psychologist directory.  
 t 1800 333 497 w [psychology.org.au](http://psychology.org.au)  
 e [contactus@psychology.org.au](mailto:contactus@psychology.org.au)

## Anglicare South East Queensland

Anglican Church's family and relationship counselling service.  
 t 1300 114 397 w [anglicaresq.org.au](http://anglicaresq.org.au) or  
[betterrelationships.org.au](http://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](http://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](http://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](http://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](http://centacarebrisbane.net.au) (Bris area)  
[centacarenq.org.au](http://centacarenq.org.au) (North Qld)  
[centacare.net](http://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](mailto: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](http://compassionatefriendsqld.org.au)  
 e [admin@tcfqld.org.au](mailto: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](http://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](http://gatewaybaptist.com.au)  
 e [gcwc@gatewaybaptist.com.au](mailto: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](http://karenlangauthor.com)  
 e [naaron2@hotmail.com](mailto: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](http://kidshelp.com.au) or [kidshelpline.com.au](http://kidshelpline.com.au)/  
[teens/get-help/webchat-counselling](http://teens/get-help/webchat-counselling)  
 e [counsellor@kidshelp.com.au](mailto: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](http://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](http://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](http://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](http://paradisekids.org.au)  
 e [services@paradisekids.org.au](mailto: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](http://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](http://www.pillarsofstrength.com.au)  
 e [info@pillarsofstrength.com.au](mailto: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](http://preciouswings.org)  
 e [info@preciouswings.org](mailto: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](http://redkite.org.au)/bereavement-support  
 e [support@redkite.org.au](mailto: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](http://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](http://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](http://scarlettmayfoundation.org.au)  
 e [info@scarlettmayfoundation.org.au](mailto: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](http://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](mailto:bereavement.ppcs@health.qld.gov.au)*