

Good  
grief,  
this  
hurts!

**GROWING UP AND GRIEVING:**  
**DEEPENING OUR UNDERSTANDING**  
**OF YOUNG PEOPLE'S GRIEF**  
**2025**

## Resource Guide



Quality of Care  
Collaborative Australia  
Delivering Education in Paediatric Palliative Care



# Welcome Message

## Acknowledgment of Country

We acknowledge the Traditional Custodians of the lands on which we live, work, and gather. We pay our deepest respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

We recognise the enduring connection First Nations' people have to land, waters, skies, and community, and the deep cultural significance of death, dying, grief, and Sorry Business. We honour the stories, ceremonies, and traditions that guide healing and remembrance, and acknowledge the strength and resilience of families and communities in times of loss.

May this guide offer space for compassion, understanding, and cultural respect.

## Self-care

Taking care of yourself is important. Allow time for rest, reflection, and activities that nurture your wellbeing—such as connecting with supportive people, spending time in nature, or practicing mindfulness. Grief and loss can be overwhelming, so giving yourself permission to pause and breathe is essential.

We also encourage you to spend some time exploring the GGTH Reflection Guide, which offers gentle prompts and strategies to help you explore feelings, find meaning, and support during difficult times.

If you're experiencing immediate distress, you can contact the below services:

- Lifeline: 13 11 14
- National Services Mental Healthline: 1800 011 511
- Beyond Blue: 1300 22 4636
- Suicide Call Back Service: 1300 659 467
- Cancer Council Helpline: 13 11 20
- Kids Help Line: 1800 55 1800

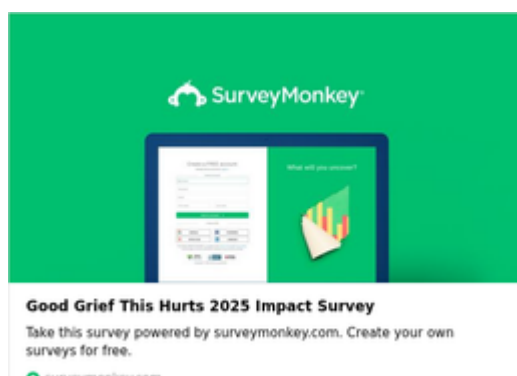


# 2025 Webinar

To view Good Grief, This Hurts - Growing up and Grieving webinar scan the QR code below or click on the tile page below.



**Please complete the post-event evaluation to help shape future Good grief, this hurts! events.**



Quality of Care  
Collaborative Australia  
Delivering Education in Paediatric Palliative Care

Developed in  
collaboration with



Children's Health Queensland  
Hospital and Health Service

# Roadmap

Click on the photo to access the presenter's resources.



**Meg Chin**

- Children, death and grief
- Resource kit for schools
- Children, young people and grief
- Children, young people and grief - tools to facilitate conversation
- Funeral tips for kids
- Sibling support
- Article - Re-imagining Childhood Grief: Children as Active Agents in a Transactional process



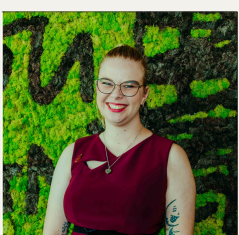
**Shelly Skinner**

- Anticipatory grief
- Things to organise - pre-death checklist
- Talking to children
- Family activities
- Memory making
- Important numbers record
- Post-death checklist
- Family checklist - how to help me in my grief
- Article - What Bereaved Children Want to Know About death and dying



**Lauren Breen**

- Working WITH grieving young people to create a world that better supports them



**Ainslie Plumb**

- You can make some noise (Ainslie's band)
- Precious Wings - legacy boxes



**Additional resources**

- Learning through loss resources
- Caresearch - Australian children's books on death and dying
- General links and resources provided by the GGTH 2025 panel



# Meg's resources

- Children, death and grief
- Resource kit for schools
- Children, young people and grief
- Children, young people and grief - tools to facilitate conversation
- Funeral tips for kids
- Sibling support
- Article - Re-imagining Childhood Grief: Children as Active Agents in a Transactional process



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# children, death and grief

Caring for a child who has been impacted by the death of someone close to them

Children are individual unique humans and world citizens. One third of the world's population is comprised of children and young people aged zero to 18 years. Caring for grieving children and families is a shared community responsibility.



newborn



infant



toddler



kinder/  
pre-school



school-aged



adolescent

## Children and death

Death literacy looks different for each child. Children need truthful information. Without truth and knowledge, we are denying children some of the very tools they need when confronted with dying, death and grief.

## Children and grief

All children, regardless of age, grieve the death of someone close to them. Each child experiences their own unique grief, impacted by internal and external factors.

Children need respect, truth, empathy and choice in their grief.

Play, language, creativity, physical activity and movement, action and story are examples of ways children manage grief and honour the person who has died.

*Children love therefore children grieve.*



## Language and empathy



Children and young people express feeling burdened and their grief minimised by the words of others - "don't cry, you're ok, be strong, look after, at least...". Language and words matter in grief support for children.

Listen to understand, rather than listening to respond.

***"In order to empathise with someone's experience you must be willing to believe them as they see it, and not how you imagine their experience to be"***

*Brené Brown, Professor and author*

## Friends and family can...



- Acknowledge a child's grief
- Communicate consistency, care and provide choice
- Respect the ongoing relationship the child has with the person who has died.

## Schools can...



- Recognise the enduring nature of grief for children
- Include death and grief in curriculum
- Understand focus and concentration for a grieving child can be challenging
- Provide training and create policies to strengthen school response
- Consult with children.

## The wider community can...



- Offer compassion, empathy, and withhold judgement
- Be open to the experiences of children
- Include children in discourse of grief, elevating children's voices, and the richness and wisdom they bring.



# resource kit for schools



Supporting students with a life-limiting condition, and their families.

This kit is designed to provide information for schools who are working with a child within their school community who has been diagnosed with a life-limiting condition.

It is designed as a reference point to some of the key considerations as you support a child or young person with a life-limiting condition and their family.

This kit can be used as a prompt or starting point to consider how you best support the child and family as well as your school community including staff, other students, and their families.

It also connects you to a range of other great sources of information from both Australia and internationally that may be useful depending on the depth of information you are seeking.

## It includes the following:

### **TIP SHEET ONE**

*Supporting the child and family –  
Diagnosis, treatment, and palliative care*

### **TIP SHEET TWO**

*Supporting the school community –  
Grief, loss, and children*

### **TIP SHEET THREE**

*Supporting your staff –  
The importance of self-care*

### **TIP SHEET FOUR**

*Supporting bereaved siblings*

### **BOOK LIST**

*A list of books that may be useful for the  
school community and the family involved.*



Very Special Kids provides specialist palliative care for children and young people with life-limiting conditions, and tailored support for their families – through life, death and bereavement.

**For more information please contact  
Very Special Kids on 1800 888 875.**



# supporting the child and family

Diagnosis, treatment and palliative care.

Finding out that a child or young person in your school community has a life-limiting condition can be an incredibly challenging experience. This resource is designed to help your school community to consider how you might work together to support the child and their family.



## Working with the child with the diagnosis/prognosis

How might you support the child in the classroom?

- *Do they need additional assistance, opportunities for time out, equipment or resources?*

Is there a place they can go for a rest or time out if needed?

- *For example a sick bay or well-being space.*

To support ongoing engagement, work with the student to understand their capacity for attendance.

- *Would reduced days or hours be more suitable?*

How can you support them if they are in hospital or away from school for extended periods of time?

- *Educationally, emotionally, socially.*

What is important to the student?

- *Often maintaining connection with peers is more important than how they manage from an academic perspective.*

Do you have a well-being person or psychologist that might be the child's main source of support at school?

Do they have any hopes or dreams that you may be key in facilitating?

- *For example, to graduate with their peers, make it to a special excursion, return to school, even if it is just for a day?*



## Working with parents of the child

The news is very difficult to hear, explore what is it/was it like for the family to process such news?

All families respond differently and have their own coping styles and strategies. It is important to respect and follow their lead in terms of how they choose to process and share information with their children, maintaining a non-judgmental approach.

How would they like the school to support their child and/or their siblings?

Work with the parents to consider all options for their child. Such as reduced days, shortened days, reduced workload, and altered expectations?

What, if anything, would the family/parents like to share with the school community? Would they like support to share this news with the community?

Do they have a preferred key contact to reduce their need to communicate their story over and over?

Explore with the parents, how the school community may be of support to them? Ideas might include:

- *Meal rosters (lunches or dinners)*
- *Support for transport for siblings, easy pick up/drop off for younger children*
- *Reduced expectations when it comes to homework etc.*
- *Additional reminders for school activities coming up*
- *Financial support (waiving fee's, fundraising).*

Additional psychological support for child and siblings. This could involve, access to a school counsellor, well-being officer, time out options during class should they be struggling with concentration or big emotions, a safe and supported space they can go to when feeling this way.



## Working with siblings

What support might the school be able to offer the siblings in the classroom and at school?

- *Is there someone they can talk to or a space they can go to if they are feeling overwhelmed, worried or in need of support/reassurance?*

Do you have a well-being person, psychologist or key person that might be the child's main source of support at school – how can they access this person?

Consider what this experience might be like for siblings.

- *How might this impact them educationally, socially, and emotionally? Do they have a supportive network of peers?*

Siblings may have times or days where they struggle with concentration, feel sad, worried, or even angry.

- *Acknowledge their feelings and help them find ways of expressing them.*

For siblings who are approaching important milestones in the school year such as VCE exams, how can you support them?

- *Have you considered special consideration, additional support to reduce their stress?*

## External resources

- Childhood Bereavement - [Supporting children before a death](#)
- Skylight - [Supporting a child when a loved one is seriously ill](#)
- Winston's Wish - [Guide to supporting grieving children in education](#)
- Palliative Care Australia - [Teachers supporting students at school](#)

# supporting the school community

Grief, loss and children.

The news that a student within your school community has been diagnosed with a life-limiting condition can impact all children, parents and staff connected to the school. Supporting the child and family directly affected is the most important. However, it is also important to understand how this news might impact the whole community.

## The impact on your school community

The way you respond to this at your school will depend on the needs of the family, their desire for sharing the news and/or their need for privacy. Different students and classes will be impacted differently according to their connection to the child, with key consideration being given to the class the child is part of, their year level, as well as the child's siblings and peers.

If the school community are aware of the child's diagnosis and life-limiting illness, then of course there will be other families who feel the need for some information and resources to enable them to support their own children.

### *Some of the key issues faced by other families include:*

- How much information do I give my child about the situation?
- How do I talk about death, dying, grief and loss with my child?
- Where can I get support for my child?
- What might prompt me to think my child needs additional support in coping with this news?

## Dispelling myths surrounding children and grief

Not all families feel comfortable having conversations about death and dying, however, it is important they can be encouraged and supported to talk with their children about death and dying.

### *Dispelling myths is a role schools can play, such myths include:*



Children do not understand death



Children do not grieve



Talking about death and dying will frighten children



Shielding children from death and dying is paramount

This in turn can assist families to open conversations and listen to the perspectives, experiences, and feelings of their children as they work to understand the death of a peer. Accessing and offering resources to families can offer information, guidance, and support as they care for their children.

All parents will choose their own path regarding how to communicate information with their children, but schools can set a positive example by having an open and honest dialogue when it comes to discussing the topic of death and dying rather than perpetuating the fear by sweeping it under the rug.

Some families will find the open dialogue around death and dying confronting and difficult. Acknowledging these feelings are important, but gently educating families about the benefits of being honest about an eventually unavoidable topic is essential. Sometimes by trying to 'protect children' from this challenging topic, we are inadvertently missing a key opportunity to educate and provide essential support for them, often allowing their imaginations to take on their own uninformed conceptualisations.

## Ways to support the school community

End-of-life care for children and young people with life-limiting conditions is often a time of great uncertainty for families. Their hope may shift and look different throughout their journey:

Schools in discussion or with permission of the child and their family may also be able to establish a way to help children support and express their grief when the child dies.

*Some examples include:*



### **Attendance at the funeral**

*If appropriate and invited by family to be involved*



### **A separate ritual at school**

*For example, candle lighting, acknowledgment at assembly, flag at half mast or a guard of honour*



### **Classroom activities**

*For example, cards, pictures, letters, drawings for the child or family*



### **Fundraising for the family or a cause identified by the family**



### **A memorial in honour of the child**

*For example, a tree, a friendship seat, a garden area, etc.*

Making it clear where children can seek support should they be struggling at school with the death of their peer is important and recognising, acknowledging, and creating a space that allows for the grieving process to occur is important.

## Some great resources for parents

- Children Grieve - [10 ways to help a grieving child](#)
- Raising Children - [Death, how to talk about it](#)
- Skylight - [Breaking bad news to children and teens](#)
- Winston's Wish - [Do children understand death?](#)
- [grief.org.au](http://grief.org.au) - [Grief Information Sheets](#)



# supporting your staff

The importance of self-care.

It is important to remember that the diagnosis of a student with a life-limiting condition and/ or the death of a child in a school community can impact everyone in that community, including your staff.

In most circumstances, staff are not necessarily trained to navigate topics such as grief from a diagnosis of a life-limiting condition or childhood death. It can be difficult to understand how this will impact their students, families and even themselves.

## The impact on your staff

*All staff will react and cope differently depending on:*



Their relationship with the child and family



Their past experiences of death and dying



The support that is available to them



Other compounding issues that may be occurring concurrently



## How can you support staff at your school?

- **Consider how you may share the news with staff in a timely but sensitive manner**
- **If imminent death is expected (or even in the case of an unexpected death), who might need to know first?**
- **Offer staff opportunity for reflection, individually and as a team**  
*This could involve reflections on the child, how the diagnosis or death has impacted the team and how everyone can support each other and students going forward*
- **Provide quality up-to-date resources on managing grief, understanding children and grief, and guidance and education on how teachers can support students and families**

- **Utilise resources such as our community and hospital teams to provide, professional development around death, dying and children**
- **Recognise that everyone will cope differently and try to avoid judgement**  
*Their own loss and grief experiences may compound this loss, or this may be their first experience of death and dying*
- **Encourage staff to look out for each other**
- **Reassure staff that they do not need to have all the answers for children**  
*It is okay to let a child know they have a good question and you will get back to them later if unsure how to answer it. Then have a discussion with parents or others involved*



## Self-care apps and resources



The headspace app makes meditation simple. Learn the skills of mindfulness and meditation by using this app for just a few minutes per day. You gain access to hundreds of meditations on everything from stress, anxiety to sleep and focus. The app also has a handy "get some headspace" reminder to encourage you to keep practicing each day.



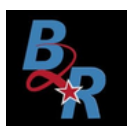
Named by Apple as the 2017 iPhone App of the Year, Calm is quickly becoming regarded as one of the best mental health apps available. Calm provides people experiencing stress and anxiety with guided meditations, sleep stories, breathing programs, and relaxing music. This app is truly universal; whether you've never tried meditation before or regularly practice, you'll find the perfect program for you.



Want to sleep better, be more mindful, improve your relationships, and become just about ten percent happier? This is the app for you. Ten percent happier has a library of over 500+ guided meditations on topics ranging from anxiety and stress to parenting and sleep, as well as videos, bite-size stories and inspiration you can listen to on the go. New content is added weekly, so you'll never tire of having to do the same meditative practice again and again.



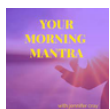
Need a happy fix? With its psychologist approved mood-training program, the Happify app is your fast-track to a good mood. Try various engaging games, activity suggestions, gratitude prompts and more to train your brain as if it were a muscle, to overcome negative thoughts. The best part? It's free!



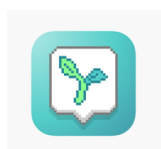
Sometimes you just need to breathe and remind yourself you are okay. Breathe2Relax is made just for that. Created by the National Centre for TeleHealth and Technology, this app is a portable stress management tool that teaches users a skill called diaphragmatic breathing. Breathe2Relax works by decreasing the body's fight or flight stress response, making it a great option for people suffering from PTSD.



Yoga should be accessible to all! That's why we have carefully curated the perfect mix of technology, teacher experience and overall yoga goodness to make Yoga Studio: Mind & Body the number one destination for health conscious individuals looking to begin their yoga journey or to take it to an all new level. All our classes come with full HD video and teacher commentary that's clear and easy to follow.



A short three minute podcast delivered daily to cut through the clutter in our busy lives.



Through lovely and encouraging push notifications, Aloe Bud brings awareness to the little important ways to take care of yourself, such as drinking water, eating and reaching out to friends. With its cute no-frills approach to self-care, it's perfect for people who deal with depression or other mental health issues that make looking after yourself difficult.

# supporting children

after the death of a sibling.



## Returning to school - things to consider

It is important to not pass any judgment on the child's choice on when they want to return to school. Some kids will want to be at school the very next day and others will really struggle to return.

Those that return quickly may do so because they need the distraction from the sadness and overwhelming feeling that home brings, especially with many visitors and funeral planning, or they simply feel the need for some sense of normality and routine in their lives.

Those that struggle to return may feel separation anxiety from their parents and loved ones, experience a fear of 'missing out' on things that are going on at home, be worried about leaving their parents who are incredibly sad, or just generally feel unsafe away from their home base.

## How can you support a child after the death of a sibling

Consider what your school may be able to do to support a child returning to school, remembering that parents are often overwhelmed, grieving and can find problem solving and troubleshooting solutions really taxing.

*Some ideas might include:*



### **Making a return to school plan with the family**

*Helping them choose a date, discussing options around shorter days or less days initially.*



### **Making a plan about how to support the child should they be having a difficult day or difficult moments**



### **Do you have a room, a space, or an activity that the child can do if they are feeling overwhelmed with sadness, grief or struggling to concentrate?**

*For example, they could have a special book they can draw or write in when they are feeling sad.*



### **Is there a message that you can deliver to the class from the child or family about what they are needing from their classmates right now**

*For many it is as simple as to be treated normally, but to also be aware that their sadness may be hard sometimes.*





**Can you help the child identify the people they might feel comfortable talking to should they need additional support**



**Think carefully about planned activities coming up on your school calendar**

*Are there any that might make things challenging for the child? For example:*

- Milestone occasions like graduations
- Classroom activities that involve discussing 'family'
- Songs that may trigger them
- Photo days (do they no longer get to have their sibling photo like they have in the past?)

*It does not mean changing these events, but it might be important to anticipate them and discuss with the family how to best support the child at these times*



**It can be helpful to talk with parents about how to best support children – especially when they are school avoidant**

*Consider, how can you support the parents to keep their child engaged at school during this challenging time?*



**Are there ways in the initial days, weeks, and months that you can relieve the family of some of the usual burdens?**

*Examples include:*

- Reduced expectations at home
- Reminders about upcoming events - Keeping up with emails at the best of times for families is hard, let alone when you are in a fog of grief
- More regular check-ins - Parents may need additional contact and reassurance that their child is doing okay.

## **Each child will cope differently**

Some children and young people may initially feel special for the additional support and attention they receive, but others may be desperate to fade into the background and just be 'normal'.

It is not unusual for children transitioning to high school that they may not want to share their story about their sibling initially – they may be needing to shake their label as the bereaved sibling or XXX's sister or brother as they seek to find their own identity outside of this label. Allow them space, time and choice about what and who they share the information with.

## **External resources**

- National Alliance for Children's Grief – [The rights of a student who is grieving](#)
- The Children's Room - [Supporting grieving siblings](#)

# useful books

Supporting families through illness and grief.

Very Special Kids recommends that professionals and/or parents familiarise themselves with each book to determine which may be the best fit for each individual situation and child. This can be done through purchasing for your professional library or seeking further information via online channels. This list is not exhaustive but can be a great starting point.

## Resources for parents

### **Remembering You: A Practical Guide for Bereaved Parents**

By Andrea Notman

### **Grief in Children: A Handbook for Adults**

By Atle Dyregrov

### **Grief in Young Children: A Handbook for Adults**

By Atle Dyregrov

### **Finding the Words**

By Dr Alan Wolfelt

### **It's okay that you're not okay**

By Megan Devine

### **Bearing the Unbearable**

By Joanne Cacciatore

### **Beyond Words**

Skylight New Zealand

## Websites



**Child Bereavement UK**

[www.childbereavementuk.org](http://www.childbereavementuk.org)



**Skylight New Zealand**

[www.skylight.org.nz](http://www.skylight.org.nz)



**Winston's Wish**

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)



**The Dougy Centre**

[www.dougy.org](http://www.dougy.org)



# useful books

Supporting families through illness and grief.

## Grief and bereavement focus

### **Life Is Like the Wind**

By Shona Innes

### **The Next Place**

By Warren Hanson

### **Ethan: What Happened to My Baby Brother?**

By Lisa White

### **A Understanding... A Place in My Heart**

By Annette Aubrey

### **What Does Dead Mean?**

By Caroline Jay

### **Grief Is Like a Snowflake**

By Julia Cook

### **Angel Birthdays**

By Erin Garay

### **A Birthday Present for Daniel**

By Juliet Cassuto Rothman

### **The Elephant in the Room**

By Amanda Edwards

### **Always and Forever**

By Alan Durant

### **Always my Brother**

By Jean Reagan

### **Molly's Memory Jar**

By Norma Spaulding

### **Sad Isn't Bad: A Good-grief Guidebook for Kids Dealing with Loss**

By Michaelene Mundy

### **Michael Rosen's Sad Book**

By Michael Rosen

### **Rabbityness**

By Jo Empson

### **Death is stupid**

By Anastasia Higginbotham

### **Muddles, Puddles and Sunshine**

By Diana Crossley

### **When dinosaurs die**

By Laurie Krasny Brown

### **Saying goodbye**

By Lisa Cooper

### **The Dead Bird**

By Margaret Wise Brown

### **The Goodbye Book**

By Todd Parr

### **Badger's Parting Gift**

By Susan Varley

### **Benny's Hat**

By Juliet Clare Bell & Dave Gray

### **My Brother**

By Dee Huxley

### **We were going to have a baby, but we had an angel instead**

By Pat Schwiebert

# useful books

Supporting families through illness and grief.

## General feelings focus

### **The Huge Bag of Worries**

By Virginia Ironside

### **The Problem with Problems**

By Rachel Rooney and Zehra Hicks

### **The Invisible String**

By Patrice Karst

### **In My Heart: A Book of Feelings**

By Jo Witek

### **Anna Angrysauros: Dinosaurs Have Feelings**

By Brian Moses

### **You, Me and the Rainbow**

By Petrea King

### **My Heart**

By Corinna Luyken

### **My Monster and Me**

By Nadiya Hussain & Ella Bailey

### **If I had a Little Dream**

By Nina Ladon & Melissa Castrillon

### **A Little Spot of Anxiety**

By Diane Alber

### **When I'm Feeling Angry, When I'm Feeling Sad, When I'm feeling Loved When I'm feeling Lonely When I'm feeling Scared**

By Trace Moroney

### **My Many Coloured Days**

By Dr Seuss

### **The Great Big Book of feelings**

By Mary Hoffman

### **Hey Warrior**

By Karen Young

### **Friendship Is Like a Seesaw**

By Shona Innes

### **A Family is like a Cake**

By Shona Innes

### **Love is like a tree**

By Shona Innes

### **The Heart and the Bottle**

By Oliver Jeffers

### **When Sadness is at Your Door**

By Eva Eland

### **Where Happiness Begins**

By Eva Eland

### **Mr Huff**

By Anna Walker

### **My Strong Mind**

By Niels van Hove

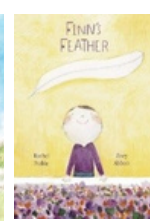
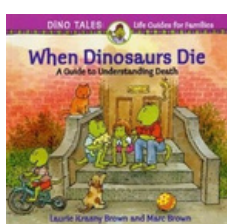
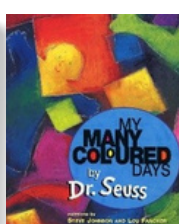
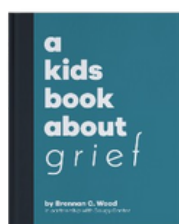
### **The Colour Monster - a story about emotions**

By Anna Llenas



# children, young people and grief

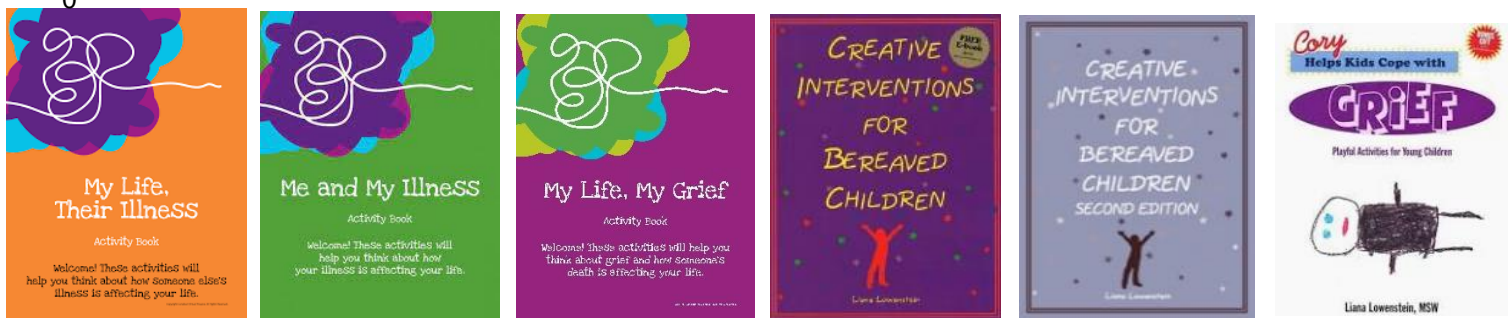
- Caring for grieving children and young people is a shared community responsibility
- All children, regardless of age, grieve the death of someone close to them
- Acknowledge a child's grief and offer compassion, empathy and withhold judgement
- Each child experiences their own unique grief, impacted by internal and external factors
- Children need respect, truth, care, consistency, empathy and choice as they grieve
- Children and young people need safe spaces to grieve. A safe space looks different for each child
- Express willingness to be open to the experiences of children
- Listen to understand, rather than listening to respond
- Recognise the enduring nature of grief for children and respect the ongoing relationship the child has with the person who has died
- Play, music, creativity, physical activity, movement, nature, pets and story are examples of ways children process, manage and make meaning in grief and honour the person who has died
- Include children in discourse of grief, elevating children's voices & the richness & wisdom they bring



# children, young people and grief

Resources and tools to facilitate conversation, activity and support

## Creative activity guides



## Conversation starters & activity cards



## Books



Tip: YouTube is a popular place for authors to read their books



# children, young people and grief



## Websites

### Creative activity guides

Me & My Illness

<https://caringtogether.life/media/sn5dibux/me-and-my-illness-book-english.pdf>

My Life, Their Illness

<https://www.kidsgrief.ca/local/staticpage/pdf/My-Life-Their-Illness-EN.pdf>

My Life, My Grief

<https://kidsgrief.ca/local/staticpage/pdf/My-Life-my-grief-workbook-FIN-Nov-21-2023.pdf>

### Activity cards

When someone dies: Activity Cards for Young Children

<https://nacg.org/product/when-someone-dies-activity-cards/>

The Children's and Youth Artists Grief Deck

<https://www.artistsliteracies.org/youthdeck>

### Organisations

National Alliance of Children's Grief NACG - <https://nacg.org/>

The Dougy Centre - [www.dougy.org/](http://www.dougy.org/)

Child Bereavement UK - [childbereavementuk.org/](http://childbereavementuk.org/)

Winston's Wish - [www.winstonswish.org](http://www.winstonswish.org)

Children and Grief Youth Network - <https://www.childrenandgrieffnetwork.com/>

AWC Grief Support - <https://andreawarnick.com/>

1000 Heart Project: <https://www.1000hearts.com.au/>



# The Rights of a Student who is Grieving

**I have the right to grieve in my own time, in my own way.**

As I grow, my needs and wants may change.

**I have the right to collaborate and design my grief support plan with school staff that understands.**

This would include me having a school staff support person identified in my grief plan and a safe place to go in school when needed.

**I have the right to share or not share about my grief.**

I have the right to ask what I share be held in confidence unless I say otherwise.

**I have the right to ask for support and not to be identified by my loss.**

I will be viewed as a student and not be identified solely by my grief. I am more than my grief.

**I have the right to have my school community respect my need to express my grief.**

My grief expressions may come at various times throughout the school day, and I may express myself in different ways as long as it does not hurt myself or others.

**I have the right to give and get support with other students at my school.**

It is important for me to have an opportunity to connect with other students including others who are grieving.

**I have the right to flexibility with deadlines to help me stay on track with my academic performance.**

My grief may necessitate adjustments to expectations with due dates.

**I have the right to choose my level of participation in events that may affect my grief.**

I have permission to not attend or participate in special events, activities, or conversations that make me uncomfortable.

# Very Special Kids Rights of the Child



As a child at Very Special Kids, I have the right to:



share what  
I think



be heard



feel safe and  
to be safe



be cared for



play, relax and  
have fun



privacy



be respected



my own culture  
and traditions



be included



be me!

[vsk.org.au](http://vsk.org.au)



## Very Special Kids Rights of the Young Person



As a young person at Very Special Kids, I have the right to:

- the best care and comfort
- be heard and listened to
- be respected, including my beliefs, religion, culture, age and gender
- ask questions and receive the information I need
- have a voice
- be treated well and to feel safe
- say no
- my privacy or company, as I choose
- assume my best interests are always considered
- choose my support people

[vsk.org.au](http://vsk.org.au)



# funeral tips for kids

Written by Aria

I am 7 years old and when I was 6, I went to my brother's funeral. I had never been to a funeral before. I thought I knew what to expect but there were lots of things I did not know about funerals. I want to help other kids prepare for a funeral. Here are some things I would like to tell you about going to a funeral for your brother or sister.

## For kids



You might cry or you might not cry, but expect to see other people crying.



You might see a lot of photos of your person, and these might make you cry.



You might have to listen to lots of different people talking.



You might see a coffin. You might see the coffin be carried or rolled on a special trolley. You might see the coffin being put into the back of a special car for coffins.



After a funeral, you might meet together with family and friends and have something to eat, and you can play with your family and friends

**You might feel many things at the funeral – sad, upset, angry, curious, interested, unsure, happy and many, many more**



# for your grown ups

- ✧✧ Please tell kids before they go to a funeral all the things they might see and hear and do and expect.
- ✧✧ Please tell kids about how their person died.
- ✧✧ Please know that sometimes siblings think it is their fault their person has died
- ✧✧ Please think about the kids at funerals and make the funeral of their person 'kid friendly'
- ✧✧ Please ask kids if they want to help with funeral preparations – we have lots of ideas and like to be involved.
- ✧✧ Please show kids the slide show of photos of their brother or sister before the funeral so they know what to expect

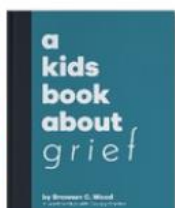
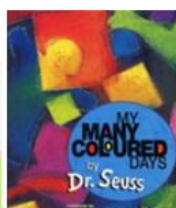
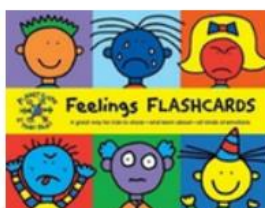
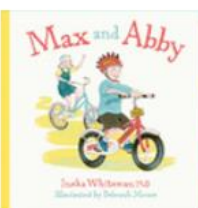
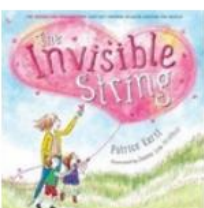
**Aria's drawing** - *A coffin with butterflies and fairy glitter*



**For more information, please contact the  
Very Special Kids support line and speak to a  
Family Support Practitioner on 03 9804 6253**

# sibling support

- Recognise, respect and acknowledge that each sibling relationship is unique
- Siblings can feel lonely and isolated
- Siblings can experience big feelings and emotions and can benefit from support in developing strategies for coping and comfort
- Listen to understand, rather than listening to respond
- Invite and include siblings in discussions, elevating their voices and the richness and wisdom they bring
- Provide siblings with honest information and opportunities for communication
- Siblings need respect, truth, care, consistency, empathy, and choice
- Express willingness to be open to the experiences of siblings
- Play, music, creativity, physical activity, movement, nature, pets and story are examples of ways children process, manage and make meaning of their experiences
- Nurture sibling relationships and acknowledge the important roles children and young people have in the family environment



# Re-Imagining Childhood Grief: Children as Active Agents in a Transactional Process

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## Abstract

Bereavement during childhood impacts children's wellbeing and biopsychosocial development. Research examining impacts and outcomes of childhood bereavement and supportive interventions has highlighted a myriad of factors that influence children's unique, complex experiences of grief, necessitating a personalized, child-centred approach. Children's grief support is underpinned by well-established grief theories studied primarily in adult populations, and stage-based developmental theories that characterise child development as "normative" and universal. We propose a rethinking that recognises: development in childhood as transactional, dynamic, and bidirectional; children as active agents; and social contexts influencing grief and development. This conceptualisation invites expanded understandings of: children's grief in response to death and non-death losses; contextual, relational influences on children's experiences of grief; ways that grieving children's rights and agency are supported and thwarted in their daily lives; and opportunities for professionals, family and community members to support grieving children with compassionate curiosity and cultural humility to nurture grief-literate communities.

## Keywords

childhood grief, bereavement, childhood agency, children's rights, transactional model of development, grief literacy, grief theory

## Introduction

"There is no universal conceptualization of childhood nor is there a universal experience of grief. Grief is both a right and privilege, yet ones that are not afforded to all children." (Traher, 2023, p. 16)

This paper was conceived and generated by a working group of 14 clinicians, researchers, and academics from nine countries: Australia, Belgium, Brazil, Canada, Germany, Israel, New Zealand, Scotland, and the United States. Our dialogue began during an in-person meeting of the International Working Group on Dying, Death, and Bereavement in Halifax, Nova Scotia, Canada, in October 2023. Whilst we had keen interest and deep investment in exploring and advancing the field of childhood grief in common, each of us brought our own perspectives, informed by our unique and varied personal, disciplinary, professional, and cultural contexts and experiences.

The opening quotation from Traher (2023) highlights the paradox between believing that grief is a natural experience that does not need to be pathologised, yet also needs our fulsome and compassionate attention at an individual child level. Our collective passion was ignited by our shared recognition of a missing central piece of the puzzle and our frustration with the inadequacies of existing conceptualisations of children and grief experienced during childhood.



In particular, we grappled with how heavily current grief support practice relies on stage-based developmental theories that are outdated, constrained and reflective of the predominantly White, male, middle class, neurotypical, North American and European children on whom these theories were based (Koller & Wheelwright, 2020). Further, well-established grief theories that have provided the basis for bereavement support programs and interventions for children, remain less well developed or integrated with foundational understandings of childhood and children's experiences (Griese et al., 2018). We felt the need to be cautious to avoid translating 'adult-model thinking to our understanding of children' (Lytje & Dyregrov, 2024, p. 2).

Notably, empirical studies of childhood bereavement have largely focused on the perceptions, outcomes, and impacts of various factors *on children*, rather than foregrounding children's active involvement, understandings of grief and related expressions of agency, and bidirectional influences on others in their lived experiences of grief. Thus, we set out to re-conceptualise grief in childhood.

In this article, the terms children and young people are used interchangeably, and along with childhood, refer to persons below the age of majority. We acknowledge that the term children may not seem to adequately include older young people or youths. We have used 'children' to maintain congruence with terms used in the field of Childhood Studies and in line with the definition of children in the United Nations Convention on the Rights of the Child (UNCRC) (United Nations Convention on the Rights of the Child, 1989). We wish to shift the conversation and our approach to understanding and supporting grieving children. In the spirit of a manifesto, we propose that there is a need for a paradigm shift to recognise and prioritise children as active moral agents in their experiences of grief.

We propose a conceptualisation emphasising agency and transactions in childhood grief as a core component. This will enable a more holistic, and complex understanding of grief as dynamic, transforming, relational, and bidirectional, which offers "unity in diversity" (Carnevale et al., 2021, p. 115). This approach -- centered on children and childhood -- invites practitioners, family and community members to recognise their responsibility and engage with opportunities to explore each young person's unique experience and needs, respond with compassionate curiosity and cultural humility, and nurture grief-literate communities.

We recognise that communities have long responded to grieving children in multiple organic ways at the point of trauma or loss as situations have presented themselves. Schools, for example, offer education about loss and grief and hold support sessions after students experience a loss. Peer support and trauma-informed responses can be adopted by sports teams and activity groups. Specialist bereavement counsellors specifically trained to support children are available. Grief-focused camps and support groups for children and their families have emerged. Web resources for grief education and support have sprung up. These initiatives have often evolved through civic and faith-based communities in response to local circumstances, identifying needs and marshalling responses often within very rapid time frames, when demands and needs are urgent. This community level response and organisation of support is a pattern seen

in many places throughout the world, and represents a movement recently championed through the concept of Compassionate Communities (Abel et al., 2018).

In our virtual and written dialogue we have continued to wrestle with how deeply ingrained old developmental theories are in our own perceptions and discourses, demonstrated by the occasional, and inevitable stumbling back into familiar ways of describing children and childhood. Despite being a relatively large working group and committed to remaining critically reflexive, we recognise the significance of our positionality, privilege, and inherent biases in our work. We are striving to acknowledge the deep diversity in human experiences, cultural contexts and meanings. As a result, we are inspired to construct a more contemporary lens through which to understand childhood grief, emphasising the significance of our openness and humility as family and community members, practitioners, researchers, and academics.

## Theoretical Framework

### *Children as Active Agents*

Alongside the negative critique of universalised age-based theories of child development, Childhood Studies scholars have advanced 'positive' arguments for re-imagining children as active moral agents, rather than immature and incapable 'human becomings' (Qvortrup, 1994).

Our conception of agency draws on Charles Taylor's early critique of behavioural views of human action in mid-20th century Anglo-American psychology (Taylor, 1985). Taylor (1989) argued that these behavioural views concealed how persons are self-interpreting agents who continually discern what is meaningful in specific situations and act in terms of their understandings of what matters. For Taylor, agents are continually interpreting what matters in light of background 'horizons of significance' and 'social imaginaries', as the surrounding community shapes their understanding of their surrounding world and how they could or should navigate it (Taylor, 1989). Persons are relationally embedded. It is also important to note that behaviors and perceptions, as well as meanings derived from experiences are culturally influenced and mediated. Children receive knowledge and observe models of how to respond through a cultural and familial lens. This may serve to determine notions of what is 'normal' or acceptable when grieving, in turn setting standards by which pathological reactions are judged within the family unit (Shapiro, 2001).

In a concept analysis of children's agency within the health literature, Montreuil and Carnevale (2015) concluded that 'children's agency could be defined as children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others. This definition entails that multiple forms of expression can be used to speak for oneself, including speech and bodily expressions, and that the capacity of children to enact agency is not dependent on adults as facilitators of agency' (Montreuil & Carnevale, 2015).

Siedlikowski et al. (2022) identified three interrelated dimensions of children's agency, which include: (a) *aspirations*, encompassing wishes and desires for themselves and others, including their broader society; (b) *concerns*, including for their own and others' wellbeing, reflecting "thwarted aspirations or worries about their aspirations not being fulfilled" (p. 667); and (c) *capacities*, relating to abilities to discern, decide, act, confront, express, and make sense of moral concerns and circumstances. Although children's agential capacity does not depend on adults, its expression is context-dependent and may be bolstered or thwarted by surrounding individuals, institutions, and circumstances (Siedlikowski et al., 2022).

As agents, children can also have views relating to their wishes for privacy and confidentiality (Noiseux et al., 2019). Children make choices all the time about what they wish to share, prefer not to share, what they will do, and how they believe their choices will impact others.

### *Transactional Model*

A transactional approach provides an alternative to the age-based developmental framework that has been so dominant within our fields, and one that cannot be dissociated from agency. The transactional model of child development was proposed in Europe and the United States in the 1970s (Sameroff, 1975, 2009), to describe the reciprocal influences of nature and nurture. Whereas stage-based theories characterise children as immature and incapable, and development as 'normative' and universal, transactional models recognise development as a dynamic bidirectional interplay in which children, and their social contexts, mutually influence each other over time (Sameroff, 2009). By conceptualising children as active agents, and development as socially contextual and rooted in relationships, transactional models invite a more holistic examination of how bidirectional interactions contribute to similarities and variations in developmental trajectories (Carnevale et al., 2021).

Whilst transactional developmental models were described in the academic world in the 1970s (Sameroff, 1975), this way of viewing development is deeply rooted and embodied in many traditional cultures that give children the space to grow and develop relationally (Sarche & Whitesell, 2012). Sameroff (2009) understands children's evolution through a lens of reciprocally amendable transactions between interdependent systems including extended family, peers, schools and community contexts. The centrality of transactions in the process of human development highlights the constant interplay between children and adults where each is affecting the other. In this model the environmental context is evolving rather than static, and is influenced by children, rather than positioning them as passive recipients.

As highlighted by Shapiro (2001), individuals construct a transactional self, influenced by elaborate interpersonal expectations from infancy, and continually evolve through a lifelong process of relational adaptation. As children interact with their family members, peers, teachers, counselors, and community members, they generate and respond to each other's signals and cues. Through these interactions – the

transactions – they co-create an environment that is influenced by their perceptions, reactions and responses to and from others, that changes over time. In this way, development is strongly influenced by such exchanges, as these transactions create the child's world and the context of their evolving self.

Rich insights advanced by anthropologists of childhood examining children's perspectives across cultural contexts (Bluebond-Langner & Korbin, 2007), as well as transactional conceptions of children's development (Sameroff, 2009), have highlighted the importance of focusing on local contexts and children's particular experiences, rather than age, towards advancing a 'thick' understanding of childhood diversities (Carnevale, 2020).

### *Family Context*

Families are crucial in a transactional conception of childhood grief, as family members' interactions, responses to, and expressions of grief influence children's own grief experiences (Webster & Skeen, 2012), reflecting familial influences on children's agential expression. Further, children's grief unfolds within families that are themselves undergoing family development processes as they adapt and face new transitions following a loss (Shapiro, 1994; Walsh & McGoldrick, 2013). This occurs within a unique structural context with multiple factors contributing to the reorganisation of roles and responsibilities, creating dynamic and fluid adaptive responses among family members (Cait, 2005; Kissane et al., 1996, 2016; Nadeau, 1998; Walsh, 2003). Grief can commence before a death as family members face a life-threatening illness and make decisions about the manner or degree to which they prepare and include children. These decisions and processes are multi-dimensional and often made more complex by families' experiences of historical and concurrent trauma (Fisher, 2003; Macpherson, 2009), all of which further supports or constrains children's opportunities for agential expression.

### **Conceptualising Agency and Transactions in Childhood Grief**

Although agency is very well-established within childhood studies, it has not permeated the health-related literature or our way of thinking in health care practice to the same extent. Stage-based developmental theory continues to shape practices in pediatric health care in many situations. By foregrounding agency, grieving is recognised as a fundamental human process that children have a right to experience and express in their own ways. That recognition demands from us more than our simple compassion.

In his description of moral agency, Taylor (1991) explained that by being human, we are all active agents and our agency is always morally oriented. We are always striving to understand what is right, what is good; that shapes the kind of aspirations that are meaningful. Significant loss and grief can disrupt a person's sense of moral order, and the way in which they understand the world around them as good, right, safe, just, connected, or not (Attig, 1996). Whether the loss is the result of the death of someone

close to them, their own or a family member's serious illness or injury, or another cause, amidst the grief and sadness questions arise about "why is this happening?" This search for meaning in the context of childhood grief has important implications for the growing self.

We propose that in the wake of that massive disruption, responses of dying and grieving children are rooted in an agential quest to make sense of what has happened (Remke, 2005), just as they are with adults (Holland et al., 2006). Children's expressions of agency, including their aspirations, concerns, and capacities (Siedlikowski et al., 2022), are central to their attempts to reconstruct social and moral order and make sense of their experiences in the face of loss and grief. Having agency means that they have aspirations in terms of how they reconcile the hardships they face; how they might want to right certain wrongs that they confront, and how they choose to share—or not—what is happening to them in order to manage actions and relationships.

Although making or finding meaning can occur in many contexts, meaning-making and explorations of meaning in the context of palliative care and grief have commonly been part of a positive care discourse that conveys optimism, and privileges a patient-centered versus family-centered approach (Barnard et al., 2022). In contrast, our transactional perspective emphasises the relational nature of our experiences in grief, and our embeddedness in systems of meaning that are not our own choice. These systems of meaning shape our identities, help us find our footing and understand what we can count on in our disrupted worlds. Therefore, our conceptualisation centres children as they strive to make sense of their experiences in a transactional manner, interacting with those around them as part of an agential quest to reconcile a disrupted moral order, access comfort, and reshape their understanding of the world they are in. This requires concerned adults to actively elicit the perspectives of children and engage in meaningful dialogues regarding a current loss, reciprocally illuminating and reshaping their respective understandings.

Children are not only *participants* in transactions. They are actively involved in shaping and contributing to their experiences and contexts. The transactions between children and those around them can support or impede this process of reconstruction, as each interaction serves to encourage or discourage, acknowledge or disenfranchise individuals' expressions of agency. This conceptualisation recognises that children have agency, which is an essential aspect of being; they influence, and are influenced by, every interaction with others and their environments.

With the recognition that every interaction with a child matters, there comes a responsibility to be aware of and responsive to their expressions of moral agency. As adults, we would then need to hold ourselves accountable for our actions, roles, and impacts on the experiences of children who are facing or managing grief, recognising that we either thwart or uplift their understandings of grief and related expressions of agency. Children command our respect and our support, our thoughtful engagement and our empathy: their voices require ethical recognition. Children are actively growing, learning, and developing, and so as a practical matter, the way they experience and come to understand grief will have significant ripple effects throughout their lives,



and through the lives of others with whom they interact over time. We advocate for the recognition of children's right to grief literate, well-informed interactions with caring others.

## Rights of Grieving Children

In recent years, the rights of children have been affirmed and articulated in the United Nations Convention on the Rights of the Child (UNCRC, 1989). This provides a foundation upon which to establish the rights of grieving children in alignment with, and advanced by, an agential conception of childhood.

The UNCRC is the most widely ratified human rights treaty. To date, the only country yet to ratify is the United States of America (Parker & Crabtree, 2023; Wagner, 2021) with Sweden, Norway and Iceland examples of the few nations that have incorporated the UNCRC into domestic law. The UNCRC sets out the fundamental human rights due to every child in the form of 54 articles grouped into the categories: *provision, protection, and participation* (Hammarberg, 1990; Jørgensen et al., 2023). These rights include those related to:

- participation (e.g., the right to be heard and to have 'due weight' attributed to their expressed views);
- having all decisions that affect them to be based on their own best interests;
- receiving information;
- expressing freely with others what they learn, think and feel;
- communicating in ways that are meaningful for them, and in alignment with their individual capacities.

The UNCRC is not without critics and tensions; Henderson-Dekort et al. (2022), Quennerstedt et al. (2018), and Sharma (2020) speak to the "ambiguity surrounding the terms rights, participation, best interests and capacity" (p.1). However, the UNCRC is the most comprehensive and universally acknowledged treaty and guiding document for children's rights.

Article 12 is of particular relevance here as it emphasises 'respect for the views of the child,' specifying that 'every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously' (UNICEF, 1989). Article 12 has been further conceptualised for practice and research with the development of the Lundy (2007). This model presents four chronological, yet intertwined and overlapping elements:

- Space: Children must be given the opportunity to express a view
- Voice: Children must be facilitated to express their views
- Audience: The view must be listened to
- Influence: The view must be acted upon, as appropriate (Lundy, 2007, p. 933).

Cuevas-Parra (2022) has further expanded the Lundy model to include ‘intersecting identities’ to refer to children’s social identities, and ‘enabling environments’ which features “...competencies, methodologies, social contexts, inclusion strategies, accountability, safeguarding and sustainability” (Cuevas-Parra, 2022, p. 373). This elaboration aims to enhance and strengthen the domains of space, voice, audience and influence for children across multiple contexts.

While the UNCRC prompts adults to recognise and acknowledge children as rights-holders, as ‘beings’ not ‘becomings’ (Uprichard, 2008), children’s capacity, agency, and best interests are impacted by the beliefs, perceptions, and attitudes of adults. As each generation explores the world through a different lens to previous generations, it is necessary to situate each child as the expert in their own lived experiences.

Incorporating the UNCRC or Article 12 into research or the practice of providing bereavement support has been very little explored. In the health care context, children have described feeling they were provided with space and voice to participate in their health care; however, that they lacked an audience and influence, leading them to feel “...like they had no autonomy or power. This was mostly attributed to having decision-making taken away in what was often framed as being in their best interests” (Davies et al., p. 11). This has been described as “epistemological oppression”, where the ethical significance of children’s voices is systemically discounted through the dominance of age-based developmental models that characterise them as immature and incapable (Carnevale, 2020). The common emphasis in practice is to attend to children’s voices with support and compassion without also recognising these voices as morally significant expressions of agency that should be attributed ethical weight in determining their best interests.

Table 1 provides examples drawing on the robust body of research and practice-based evidence related to children’s grief. We assert that, as a basic minimum, children have rights to:

Supporting children’s grief experiences in these ways ultimately promotes children’s individual wellbeing. Such support will optimally promote opportunities for transactional learning in the context of each individual’s development. Respecting children’s rights in this manner can help ensure an individualised, child-centered and grief-informed understanding of their best interests.

## Implications of Agency and Transactions in Childhood Grief

If we recognise children as active agents who mutually influence and are influenced by their close relationships, communities, and cultural contexts, it follows that their complex and unique experiences of grief will be both expressed and shaped in each of those contexts. Therefore, implications for supporting grieving children are relevant and applicable to all adults with whom they interact, whether they are family, friends, members of a shared community, educators, health care professionals, counsellors, or others. By equipping all the adults in childrens’ lives with a deeper understanding of grief and agency in childhood, comprehensive support can be provided by grief-literate,

**Table 1.** Children's Grief-Related Rights.

Grief literacy	Learn words and concepts to help them understand their own grief experiences with approaches that match their style of learning Live in an environment with grief and death literacy to help protect from isolation and misconceptions Receive practical, emotional, spiritual and social support from a grief- and emotionally- literate community
Information-sharing	Choose what information they have access to and have it shared in ways that are clear and comprehensible (Dalton et al., 2019) Select what information they share with others and keep private (Noiseux et al., 2019)
Expression	Have ongoing opportunities to express thoughts, feelings, questions, and worries Experience and express grief in ways that are true and meaningful for them
Inclusion	Be involved in decision making related to dying, death and bereavement Participate in grief rituals, including funerals, memorials, or celebrations of life, in ways that they choose
Agency and influence	Have their agency, including their capacities to influence their families and social environments, respected Be recognised as people who have something to contribute towards others' experiences and understandings of grief
Supports	Receive support for their carers to help with day-to-day tasks and activities that have been affected by the death or loss of an important person Have ongoing opportunities to engage in meaningful activities and meaning-making processes Access necessary formal and informal supports

compassionate communities. We propose that adults support grieving children's rights and agential expression by: leading, following, and listening; information-sharing and inclusion; making sense of their experiences; valuing play; and finally, research and policy recommendations.

### *Leading, following, and Listening to Grieving Children*

Respecting children's rights and agency requires adults to actively elicit and listen to children's perspectives, concerns, preferences, and wishes, with a genuine desire to understand and honour their views (Lundy, 2007). However, legitimately creating "space" to express a view requires that adults sometimes take the lead to initiate conversations about death, loss, and grief, demonstrating our willingness to be open and vulnerable. Deferring to children with the perspective that, "we'll talk about it when they bring it up," places the onus on them to initiate daunting conversations, and disregards children's tendency to engage in mutual pretense, mirroring the behaviours of adults in their lives. Instead, adults need to model how to engage in important conversations even if they feel uncertain or uncomfortable doing so.

After setting the stage and opening a dialogue, adults can respect children's rights and agency by listening intently and shifting to follow children's lead in terms of how much and which information they want to hear, when, where, with whom, as well as guiding the pace. This active listening also requires adults to treat children's thoughts, feelings, questions, and concerns seriously. For example, when a child asks, "how will he pee in the coffin?" or "will worms crawl all over her?" they deserve a thoughtful response that recognises the child's legitimate concern rather than treating it as "cute" and insignificant. Treating children's questions as important and meaningful conveys respect and encourages them to express their thoughts and feelings as they arise.

Children also need adults to listen and follow their lead as they oscillate in their grief, alternating between focusing on and away from contrasting thoughts and feelings, or between play and distress, as they grieve (Stroebe & Schut, 2010). Rather than re-directing them to "be strong," or "stay positive," adults can ensure that children have the freedom to "puddle-jump" (Child Bereavement UK, ) in and out of intense moments of grief or oscillate back and forth between focusing on the present and future, and grieving and mourning the losses they have experienced (Stroebe & Schut, 2010). Caring adults can honour children's agential expression in the choices they make about what, when, and how often to focus on different elements of their grief, how, and with whom.

In the absence of an understanding of grief in general and particularly in childhood, this oscillation is sometimes misinterpreted as denial or a lack of understanding of death; in contrast, a grief-literate approach recognises this process as a natural means of self-regulation amidst the emotional intensity of grief in childhood. Adults can support children's capacities by recognising their behaviours as clues or expressions of their needs, and offering their supportive presence with children experiencing the full range of emotions they may have without trying to "correct" them.

### *Information-Sharing and Inclusion*

Researchers examining parents' feelings of relative comfort and preparedness to address their children's questions and needs related to a family member's serious illness have found that many parents struggle to take their children's views into account prior to the parent's death (Dalton et al., 2019; Eklund et al., 2020). Impulses to protect children from the immensity of grief often result in inadequate attention paid to the child's needs and cues, for example, such that many avoid telling children about a parental or sibling terminal diagnosis until the end-of-life is near (Dalton et al., 2019; Stein et al., 2019).

Health care professionals are often positioned to advise and support parents in preparing their children for a family member's impending death, with many parents seeking this type of support (Dalton et al., 2019). In addition to supporting parents with early discussions, health care providers are well placed to advocate for managing visitors in a manner that protects adequate one-on-one time for children and their dying parent or sibling, enabling children to say or do what feels important to them. However,

a number of challenges have been reported, including health care providers' lack of training, comfort, or familiarity supporting children's participation in communication and decision-making as a parent's death approaches, particularly in the context of family members' grief, complex dynamics, cultural and communicative norms (Dalton et al., 2019). This is especially challenging when children are perceived to be overwhelmed by the experience (Morris et al., 2017; Philips, 2014).

Contrasting these protective intentions, children demonstrate their capacities through their play to actively engage in maintaining their relationships with dead loved ones and have the resources to resist harmful outcomes by creating positive biographical transitions before and after parental death when they have opportunities for support and inclusion (Turner, 2020). Children also have their own agential aspirations related to attending funerals and other rituals when adults question the appropriateness of their presence. For instance, children may wish to support a bereaved friend who they fear will feel alone; confirm that the person is 'really dead' and it's not a mistake; feel the sense of security afforded by family gathering around them; or simply to take part in compelling, meaningful events within their family or community.

Children also have rights and preferences related to whether and what information about their experience they share with others, balancing the tension between a desire for others to be sensitive and supportive, while maintaining their own privacy (Canadian Virtual, 2022). When so much is beyond their control, grieving children can exercise agency and control over what they share and with whom (Remke, 2005). It is critical that others do not thwart children's agency by sharing information with peers or community members -- even with protective intentions -- without exploring their own personal wishes and preferences, or to push children to express their most vulnerable thoughts and feelings before they feel able to do so.

It is clear that children have aspirations and capacities of their own, including to be able to shape their own narratives more than they are typically given credit for. To support these efforts, children have repeatedly expressed their desire to have access to information and a voice in decision-making in order for them to make informed and meaningful choices about their own involvement when someone is dying or has died (Chowns, 2013; Davies et al., 2024; Eklund et al., 2020). It is important to be responsive to each child's unique preferences.

### *Making Sense of Their Experiences*

Grieving children need to be met with compassionate understanding and feedback in their social environments. In the absence of caring others with whom children feel safe and comfortable to express themselves, feel heard, and supported, their attempts to make sense of a death or non-death loss in isolation can lead them to internalise harmful messages. For example, if children have not been invited to express their thoughts and feelings, even if the reasons for this are well-intended, they may interpret it as "nobody cares what I have to say," "nobody talks about this," or "I don't matter." If they do not have people around them modelling and talking about their own grief, they may



imagine, “there must be something wrong with me if I am upset by this.” If no one is exploring their beliefs about life and death, helping them to navigate uncertainty, mortality, and vulnerability, children may feel, “anybody can die at any time, it seems like there’s no order or sense to the world around me.”

For those coming from communities or personal experiences that have taught: “good things happen to good people,” this death, loss, or sense of injustice disrupts the moral order, prompting reflections that may be internalised, such as, “why did this happen to me?” or “what did I do to deserve this?” When children are excluded from difficult conversations in an attempt to protect them, children’s agency, access to information and support are thwarted, leaving them to infer their own explanations. Often, this leads to feelings of being somehow responsible for an illness, death, or suffering. Facing this experience without caring adults to explore and clarify children’s perceptions and understandings can contribute to considerable emotional conflict or distress.

Caring adults in a child’s life can engage with them to support their making sense of these existential questions as part of a process that transforms over time. Contrasting an approach to “meaning-making” as a psychosocial intervention, this orientation to “making sense” emphasises and honours children’s rights to information and support, and their agential efforts and capacities to understand and grapple with complex information and great unknowns. This is an essential element and facilitator of grief literacy: offering a knowledgeable and compassionate presence and responses to children as they confront losses (Breen et al., 2022).

### *Valuing Play*

Adults can support children’s rights and agential expression by creating and valuing opportunities to engage in play. Contrary to the dominant conception of play as a frivolous way of occupying or wasting time, or taking one’s mind off things, playfulness is an important, meaningful means of expressing agency (Hausfater et al., 2024). For example, adolescents have demonstrated that play can be revealing, creating an opportunity for expressing dimensions of agency that are systematically suppressed by social norms that devalue all that is associated with childhood as frivolous and unimportant (Hausfater et al., 2024).

We encourage the adoption of a practice-oriented recognition of play as a powerful transactional, reciprocal opportunity between children, but also children and older people. Play offers a means of making sense of stressful events that occurred by rehearsing or replaying them to process information; rebuilding a sense of control by reconstructing events in the way that a child may wish they had unfolded; expressing strong feelings or intense energy; finding comfort in familiar or imaginary play. Each of these forms of play can help children’s processing and adapting as they grieve, supporting the natural oscillation of grief and the development of a coherent narrative of their experiences. By engaging in, or observing children’s play, and by following their lead and paying attention to what is being expressed, adults have an opportunity to better understand children’s perceptions and needs.

## Research and Policy

Current initiatives within childhood research highlight political dimensions of young people's agency. Specifically, as agents, young people's interests and capacities are not limited solely to matters that affect them directly. We have noted the growing involvement of young people as advisors or partners in the development of practices, policies and research that relate to the experiences of their broader communities. Initiatives including structural innovations like child/youth advisory councils, and youth led protests for environmental justice have demonstrated ways in which youth engagement can be promoted effectively and respectfully, offering youth avenues for agency that go beyond mere tokenism. Furthermore, [Lichtenthal et al. \(2024\)](#) urge bereavement care and support be considered globally as a public health priority, both from an economic and resource perspective and as a public health issue. Recognising the benefits of pre- and post-death support and increasing grief literate compassionate communities benefits children. Alternatively, "the effect of inadequate bereavement care disproportionately disadvantages vulnerable groups, including those living in resource-constrained settings" ([Lichtenthal et al., 2024](#), p. e270). We recommend that future development of practices, policies and research related to children's grief should be undertaken with meaningful partnerships with young people.

## Limitations

We recognise in this proposal that we speak from an extremely privileged position that is not accessible to many carers or supporters of children. We also appreciate that many carers and practitioners around the world instinctively take children's agency as a given in their approach and in their communication with the children in their sphere of influence. However, we also recognise that there is a grave risk of inequality of adherence in the practice of respecting children's rights.

Inequality is deeply embedded in the experience of childhood bereavement. Children born into the lowest income households are at greatest risk of being bereaved of a parent or sibling ([Paul & Vaswani, 2020](#)), as are those with racialised and historically marginalised status ([Howard, 2023](#)). They are also at greater risk of being unable to receive support to process grief due to racism and historically marginalised status ([Bordere, 2019](#)).

Whilst we have explored understandings of bereavement as an individual and family experience, it is also a universal experience which is profoundly influenced by social context, making this also a public health issue. We cannot present an empirically tested research hypothesis but we do wish to contribute to the debate and encourage readers to apply this to their own working contexts and share feedback with us to inform the continued evolution of our thinking.

## Conclusion

While undoubtedly, the death of a parent or sibling causes considerable distress for children, the transactional model argues that an individual's ability to adapt to

challenges and problems arises from the transactions - interactions - that occur between them and their environment (Sameroff, 2009). As children navigate countless interactions, including the avoidances and silences surrounding death and grief, they constantly observe, consider, interact with, and influence their environment, through their conscious or unconscious choices about what to say, do, or express. This is at the heart of their agency.

To support grieving children, it is important to understand that every reciprocal transaction contributes to children's interpreted and internalised narratives about grief and life. After a loss, it is critical to be aware of the fact that children do grieve, that they impact and are impacted by those around them, reflecting influences on their social environments at any and every age. Their impressions, the feedback they receive, the messages they interpret about what is and is not deemed acceptable by those around them, can have immediate and life-long influences on their thoughts, behaviours, emotional and physical wellbeing.

We propose that rather than placing the burden solely on children to seek support, adults have responsibilities to engage in a collaborative process whereby children have opportunities to express their interests and needs. Adults should also reinforce resources that inherently exist in communities to support grieving children and to empower those connections and relationships. Ultimately, acknowledging that in many contexts children's rights to grieve may not be recognised (Traher, 2023), we encourage adults to uphold children's agency in their grieving.

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## Author Biographies

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**Meg Chin**, MSW, PhD candidate is a senior clinical social worker and Family Support Team Leader at Very Special Kids, a children's hospice and family support organisation in Melbourne, Australia. Meg works alongside families providing support during illness, dying, death and bereavement, and specialises in play-based counselling with children and young people. Meg is a PhD candidate at the University of Melbourne, researching the lived experiences of children aged 5 through 12 who have had a sibling die from a life-limiting condition. Meg has over 15 years of experience in paediatric palliative care and interests in children's agency and rights, childhood grief, children's advisory groups, and death and grief literacy. Meg is EPEC-Pediatrics trained and a member of the International Work Group on Death, Dying and Bereavement.

**Georg Bollig**, MD, MAS (Palliative Care), PhD, DEAA is a physician and researcher. After medical studies at the universities of Cologne, Vienna and Seattle he became a specialist in anaesthesiology, pain therapy and palliative care. He received a Master degree in Palliative Care and Organisational Ethics from the University Klagenfurt/IFF Vienna. His PhD at the University of Bergen, Norway was about Palliative Care, ethical challenges and end-of-life decision-making in nursing homes. From 2016 to 2022 he has been working as senior consultant in Palliative Medicine at the University hospital of Southern Jutland and as Clinical Associate Professor in Palliative Care at the University of Southern Denmark. Currently he works as senior consultant in Palliative Medicine and head of Palliative Medicine at the Academic teaching hospital Helios Klinikum Schleswig in Germany. In addition to his clinical work Georg is a research fellow at the Department of Palliative Medicine, University of Cologne, Faculty of Medicine and University Hospital, Cologne, Germany. Georg has first published the idea of a Last Aid Course and is the leader of the International Last Aid working group and the Last Aid research Group International (LARGI). His main current research interests are public palliative care education (PPCE), Last Aid Courses and tele-palliative care.

**Cheryl-Anne Cait**, MSW, PhD is an Associate Professor at the Faculty of Social Work at Wilfrid Laurier University. She teaches in the MSW and PhD programs as well as in the W2B program, a program where university level courses are taught in correctional institutions. Her research looks at death, dying, and adolescent grief and identity and research projects also involve exploring community-based approaches to hospice and palliative care, specifically looking at volunteer recruitment, rural issues and diversity.

**Franco A. Carnevale** is a nurse, psychologist, and clinical ethicist, as well as a full professor in the Ingram School of Nursing, McGill University. He is the principal investigator for VOICE: Views On Interdisciplinary Childhood Ethics. VOICE is an international initiative to advance knowledge and practices relating to ethical concerns in childhood.

**Jody Chrastek**, RN, DNP, CHPN, FPCN, is the Nursing supervisor for Pain, Palliative Care and Integrative Medicine for Children's Minnesota, USA. She has worked in hospice and palliative care for over 30 years, 20 of those in Pediatric palliative care, focusing on care in the community. She has published and presented on these subjects nationally and internationally. Her Doctorate in Nursing Practice work focused on training Adult hospice programs to provide hospice care for children in their communities. She is a Fellow of Palliative Care Nursing and a Certified Hospice and Palliative Nurse.

**Bianca Lavorgna**, BBSci, GradCertBerCouns, MCouns&PsychTh, CBP, is an experienced Bereavement Counsellor, Educator, Clinical Supervisor, and Applied Suicide Intervention Skills Trainer with expertise in developing, delivering, and coordinating support services and programs. Bianca comes with specialist knowledge and

experience in working with suicide bereavement, children, and adolescents. She is the co-author of *The Yellow Leaf*, a children's book that aims to help families to understand that grief is not linear and that there is no perfect way to grieve. Bianca is passionate about providing bereavement support, companionship, advocacy, and education, creating a community where grief can be talked about openly and support can be provided among friends, family, and wider society.

**Catriona Macpherson** is a Specialist Palliative Care Children and Families practitioner in NHS fife, Scotland. She supports families from diagnosis to as long as required following parental bereavement. She has an interest in narrative research and is currently engaged in practitioner research with her team.

**Stacy S. Remke**, MSW, LICSW, APHSW-C, FNAP is a Senior Clinical Teaching Specialist at the University of Minnesota's School of Social Work. Her clinical experience includes 27 years as a pediatric social worker, assisting children with life threatening and chronic, complex conditions and their families in home, community and hospital settings. She was a founder of the palliative care service at Children's Hospitals and Clinics of Minnesota, one of the first pediatric palliative care programs in the US. Stacy was a Co-Investigator for the NCI funded curriculum development project, "EPEC-Pediatrics" and has taught the curriculum nationally and internationally. Stacy has contributed extensively to the knowledge base for the field of pediatric palliative care. She served on the national Advisory Board for NHPCO's ChiPPS Pediatric interest group, and as a faculty member for Center to Advance Palliative Care's (CAPC) PCLC at Children's Minnesota. Stacy served on the Board for Social Work Hospice and Palliative Network (SWHPN), is a certified hospice and palliative care social work specialist (APHSW-C). As a member of The International Workgroup on Death, Dying and Bereavement (IWGDDDB) she is focusing on grief literacy, child loss and childhood bereavement issues. She has been inducted into the National Academies of Practice as a Fellow.

**Lies Scaut** is a Social Worker, Marital and Family Therapist, Grief Therapist, Hypnotherapist, Lecturer and coordinator at PXL University (Hasselt, Belgium) and Faculty Member of the Portland Institute for Loss and Transition. As an author, she has written several books on children and grief. Additionally, she developed a series of creative arts techniques for grief counseling with children, families and schools.

**Dr Jane Skeen** MNZM is a graduate of the University of Auckland, Medical School and received her paediatric training at the former Princess Mary Hospital, Auckland, New Zealand. Paediatric Oncologist Starship Blood and Cancer Centre. Starship Children's Health Auckland, New Zealand (1979- December 2021 when retired). Sub-specialty interests in Late Effects of Childhood Cancer, Paediatric Palliative Care, Paediatric renal and hepatic tumours. Member of the National Child Cancer Network Late Effects, Children's Cancer Registry and Pacific Island (Chair 2009-2021) working groups. Committed to improving the outcomes of children with cancer in the Pacific (including the provision of Palliative Care) and visited and worked with the Pacific

Health professionals in Tonga, Vanuatu and Samoa 2006-2021. New Zealand Child Cancer Foundation Life member (2001), Board member and Convenor Health Professional Sub-committee till 2018. Member International Work Group Death Dying and Bereavement= board member from 2011-2018, 2023-present. Recognised as Fellow IWG (FIWGddb) 2023. Co-author with Dr M Louise Webster of the chapter "*Communication with Children: their understanding, information needs and processes.*" in Pediatric Psych-oncology (2<sup>nd</sup> edition). January 2023- recognized as a Member of the New Zealand Order of Merit (MNZM)- for services to children with cancer.

**Regina Szylit**, PhD, RN, FAAN is a Professor and Ex-Dean at the University of Sao Paulo, School of Nursing in Sao Paulo, Brazil. She is Principal Investigator in the Institute of Advanced Studies of the University of São Paulo, member and fellow of the International Work Group in Death, Dying and Bereavement (IWG) and a Country Liaison Coordinator in the International Family Nursing Association. She has developed an integrated program and process of education, research, and clinical practice aimed to improve nursing care to families of children in palliative care.

**Camara van Breemen** is a Nurse Practitioner and Play Therapist at Canuck Place Children's Hospice and British Columbia Children's Hospital. She provides pediatric palliative care pain and symptom management, advance care planning, and end of life care to children with serious illness and their families throughout British Columbia. She is faculty in the Division of Medicine – Palliative care department, University of British Columbia and dedicates much time to the training of health care professionals in pediatric palliative care competencies across Canada and Internationally.

**Ronit Shalev**, PhD, Head of Education Department and Educational Counselling Department of Max Stern Academic College of Emek Yezreel. She is co-chair of the Israeli forum - governmental, societal, and academic organizations, and is responsible for training volunteers and professional knowledge at "Out of the Depth", a non-profit organization that helps bereaved individuals cope with grief and loss. Additionally, she is a therapist for integrative mind-body psychotherapy at HaEmek Hospital, Afula's clinic for children and adolescents. She is co-editor of two books (2024): delivering bad news and a book on body-mind psychotherapy. She is also an active artist.

# Shelly's resources

- Anticipatory grief
- Things to organise - pre-death checklist
- Talking to children
- Family activities
- Memory making
- Important numbers record
- Post-death checklist
- Family checklist - how to help me in my grief
- Article - What Bereaved Children Want to Know About death and dying



[Home - Lionheart Camp For Kids](#)

Good  
grief,  
this  
hurts!



# ANTICIPATORY GRIEF



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## CHANGE

There is something about change. Especially unexpected changes that are outside of our control. The unwanted coming in and changing the direction of our lives. Changing our hopes and plans for the future. And quite often this change enters, in a split second of time. The blood test, the Doctor's appointment, the diagnosis. It breaks apart our world from what it was before, to now 'the after'. Change can bring chaos, uncertainty, the unknown, and it rocks our sense of security, the predictable, the stable.

All of a sudden, the world around us can feel really unsafe. Some changes bring a ticking time bomb with them, putting us on a new path and highlighting that there is more pain and struggle ahead, even when there is a small glimmer of hope, there is also the looming shadow that the worse outcome could very well be the path you end up on. This in turn leads to more change, more uncertainty, more unknown.

## THE WEIGHT

A part of you is in a battle, for getting through each day, to holding onto the hope, to keeping things 'normal' for the kids and not making them worry. But under the weight of holding it all, is so many different emotions, all swirling in the background, emotions that might not have a lot of time or space to be acknowledged, let alone felt.

This is what anticipatory grief is made up of. That sense of unwanted change, the heaviness of the emotions under the surface, the deep fear, the dread, the anger and the desire to avoid it all. Grief can be messy and uncomfortable and overwhelming for us, as adults, who hold a deeper understanding of what is happening, however, for children it can be really confusing.

## CHILDREN AND ANTICIPATORY GRIEF

Although your children may not fully understand what these changes have brought into your family and what it might mean for the future, they are remarkably perceptive and they will pick up that it is impacting you, even if they don't fully understand the details. Their own sense of change and the unknown may also stir up their own emotions of pending grief.

Children, however, often don't know how to give voice to the different feelings they are holding and will often express these through their behaviour. Often with each family member expressing these feelings in different ways. Everything that each family member is feeling is valid and important in response to their whole world changing. Keep holding space for how each person is processing these changes and the feelings this is bringing to the surface.

# PRE-DEATH CHECKLIST



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

Families have often spoken to us about the difficulties and unknown complications around the legal, financial, and practical requirements of being an executor. We have compiled a list of things that may make this a little clearer.

## FINANCIAL & PRACTICAL STEPS

- Review what accounts are held in your Important Person's name.
- Consider any accounts that can be closed.
- Create a list of all debts, along with assets and income.
- Gather all important documents into a master folder or an Important Numbers Record.
- Make a note of where any other important documents may be stored.
- Review your Important Person's and your own employment entitlements, policy, contract, and leave.
- Check your life insurance policies first before rolling superannuation into one account.
- Check if the superannuation fund has a Binding Death Benefit Nomination.
- Check life insurance and superannuation policies for claim processes.
- Check if there is funeral insurance or end-of-life care.

## END OF LIFE & FUNERAL

- Review the Last Will and Testament.
- Explore your Important Person's preferences for end-of-life arrangements.
- Create a list of people they would like to notify.
- Explore funeral/memorial plans and preferences.

## LEGAL CONSIDERATIONS

- Does your Important Person have a Last Will & Testament?
- Location and storage of the Will.
- Who has been appointed as the executor?
- Have you been appointed with enduring power of attorney?
- Is there an End of Life Plan or Advanced Care Directive?
- If your Important Person has a Do Not Resuscitate order in place, make sure you have the original or certified copies available.
- Body Donation Consent Form if they wish to be an organ donor.

## DIGITAL COMMITMENTS

- Record all logins and passwords
- List all ongoing subscriptions
- List any professional and personal memberships
- Close down any unused apps, accounts, storage, and subscriptions
- Consider when digital accounts will be closed

# TALKING TO CHILDREN



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## TOUGH CONVERSATIONS

When death becomes a certainty, it's important to have conversations with your child to prepare them. It can be helpful to explain the practical side of how a body works and what a body needs to work well can give a good foundation to talk about death. Consider exploring when the body does not have essential needs met, it cannot continue to live. Drawing from encounters with death that the child may have experienced (through a pet, snail, spider, ant, or bird, etc.) can also add to their understanding. It can be helpful to explain that when death occurs, the body no longer breathes or moves, and the person can no longer talk, smile, or touch you. Although your child can still talk to them and touch them.

Keep in mind that children are egocentric in their understanding of life (particularly heightened at different developmental stages), so they can often make assumptions about what is happening around them and their own power in causing it.

Reaffirm for them that their Important Person loved them (if a true reflection) and did not want to leave them. Invite their questions and ask what they understand first before providing clarity. Let them know it is an open and ongoing conversation, and that they can ask questions at any time.

## CHRONIC & TERMINAL ILLNESS

The diagnosis changes everything and begins a gruelling journey. There can be so much shock and a sense of suddenness around a diagnosis. From there, the changes that occur may be slow and subtle, or drastic and aggressive. Children will pick up on these changes, particularly if they are physical changes, although they may not fully understand them.

The concept of illness might be understood from a general perspective depending on the child's age and development, but the intricacies are often outside their scope. Even though there is a strong desire to protect children from difficulties and pain, it is important that children have a basic understanding of the illness and what is happening. When information is kept from them, they will often sense something is happening that they are not being told. Children are also good at catching snippets of adult conversations around them. When this happens, children will often 'fill in the gaps' based on their own understanding and imagination, which can often be a lot scarier for them than the reality. When explaining the situation to your child, you want to provide them with age-appropriate, clear, and honest information.

Encourage any questions they may have and let them know they can ask questions at any time. Even if you are unsure how to answer a question, thank them for asking and know it's ok to say you don't know or need time to think about it and get back to them. Having open communication, where your child can come to you with their questions or concerns, will lessen the intensity of their fear and build safety and trust.

# TALKING TO CHILDREN



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## PENDING GRIEF

Allow your child time (if possible) to process your conversation around death. Invite questions if they have any. Give your child some options around ways to express their emotions and connection to the person who is dying. Children often process their emotions through art, imaginative play, and role-playing. See if your child would like to draw a picture or write a letter (with your help) to the person who is dying. However, do not pressure them to do so if they decide they do not want to.

## PRACTICALITIES AROUND THE DEATH

Deciding whether your child should be present for the death can be a difficult decision. There is no right or wrong in this, and the decision needs to be made based on who your child is and the understanding you feel they have around death. If you decide for your child to be present, it is really important that you prepare them as much as you can (in an age-appropriate way). Let them know what they will see, hear, and smell at the hospital/hospice/house. Let them know who will be present (family members, nurses, doctors, religious personnel, friends, etc.). Let them know that this will be the last time they will be able to see and talk to the person (in their body). That the person may not be very alert, or they may be for a short time before their body slows down. The person may have periods of sleeping and being still, and that their body may become cold to the touch because their body is shutting down (like a TV or phone turning off). Then the person will stop breathing, and their heart will stop beating, which means that they have died.

There can often be a quiet or hush after someone dies, and people around them may release different emotions, including sadness and tears. Let your child know that you will be with them the whole time, that you love them, and that you know this might be a bit confusing for them (depending on their age). If your family has any particular spiritual or cultural practices around death or with the body after death occurs, explain what these might look like.

Give your child a choice about touching the body once the death has occurred, and never force or pressure them to 'say goodbye' or touch the body if they choose not to. If you decide for your child not to be present, still give them a simple (age-appropriate) idea of what might take place and, again, invite any questions they might have.



# FAMILY ACTIVITIES



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

When there is a warning about death approaching, it gives families one priceless resource—time. Time to prepare. Time to be intentional. Time to capture. Time to express. Time to sow into the future. But having that warning also stirs up a mix of reflections on the past, one's own family, childhood and adult years; along with the present; and wonderings about the future, hope for your loved ones, and grief about not being there.

Below are some ideas for different family activities to do in the present that reflect on both the past and the future. They create memories and help pour into the present time together. Of course, some of these activities may be limited by physical and mental capacity, pain tolerance/management, and energy levels. Choose a few activities that resonate with where you and your family are, and start there.

## FAMILY FUN

- Play: Would you rather?
- If you had \$1 million, what would you do? Come up with three different crazy ideas each.
- Talking Point Cards.
- Play a board game or a card game.
- Create a family artwork together—each person contributing or drawing something.
- Or create a canvas with everyone's name & fingerprints on it.

## JOYFUL MOMENTS

- Family Talent Show: Each family member can showcase a hidden talent, whether it's singing, dancing, telling jokes, or performing a magic trick.
- Build a Blanket Fort: Create a cosy, indoor fort using blankets and cushions, and spend time inside watching movies, reading stories, or relaxing together.
- Bake Together: Pick a fun recipe, like cupcakes or cookies, and bake as a family.
- Create a Family Music Playlist: Each family member picks a few songs, and together you create a playlist that can be played during special moments or just for fun.
- Photo Booth Fun: Set up a DIY photo booth with silly props and take funny family photos.

## CREATING NEW MEMORIES

- Write letters to future ages/stages for each family member.
- Create new memories—what are some places they always wanted to visit?
- Go to their favourite place & do their favourite activity there.
- Eat their favourite food (at home or at a restaurant).
- Listen to their favourite music.
- Watch their favourite movies.
- Read/listen to their favourite books.
- Dream of the future—their dreams for the family, your dreams for the future/yourself.

## REFLECTING ON MEMORIES

- Go through photo albums & talk about memories.
- Pick out favourite photos to blow up, frame, or scrapbook.
- Ask questions about the Important Person's likes/dislikes, funniest memories, and hardest times:
  - What was their favourite childhood activity?
  - What was one of their biggest challenges?
  - Who were their closest friends?
  - What moment do they wish they could redo? Or re-experience?
  - What was one thing/memory that made them laugh until they cried?

# FAMILY ACTIVITIES



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## CELEBRATING LIFE

- Create a Memory Box: Fill it with meaningful items such as letters, trinkets, and mementos.
- Record a Legacy Video: Have your Important Person share stories, advice, and messages for loved ones on video to be watched in the future.
- Write a Family Biography: Collaborate to document the life of your Important Person, including significant moments, relationships, and lessons they've learned.
- Plant a Tree or Garden: As a living tribute to your Important Person, plant something in their honour that will grow and be nurtured for years to come.
- Create a Family Recipe Book: Include their favourite dishes along with stories or memories tied to these meals.

## RECORDING FAMILY HISTORY

- Is there any family history that is important to record or capture?
- Family stories about the Important Person's parents, siblings, or grandparents?
- Medical conditions or concerns/history?
- The Important Person's own memories or grief about people in their past?

## LIFE LESSONS & LEGACY

- Ask & record what three major life lessons/truths your Important Person has learned throughout their life.
- Is there a symbol that is meaningful to your Important Person (animal, song, place, weather, smell, etc.)? Examples: 'Twinkle Twinkle Little Star', 'Uptown Funk', ladybugs, butterflies, kookaburras, dolphins, beach, hills, stormy weather, just before it rains, mown grass, hot coffee, frangipanis, etc.
- Read 'The Invisible String' together (or another storybook about connection).

## EMBRACE THE PRESENT

- Spend Time Outdoors: If possible, take small trips to places your Important Person loves, like parks, gardens, or beaches, for fresh air and peace.
- Hold a Movie Marathon: Watch their all-time favourite films together.
- Have a Themed Family Dinner: Cook your Important Person's favourite meal or cuisine.
- Daily Rituals: Create small, meaningful daily rituals like morning coffee together, sharing a favourite song, or reading aloud from a beloved book.





# MEMORY MAKING



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

Facing our mortality is not easy, and in Australia and many Western cultures, it is something that is not spoken about and is often avoided. It is a difficult space to sit in, thinking about the future without us physically being in it—thinking of our family's future without us.

Something that bereaved families often mention is the desire to just spend one more hour with their Important Person; one more conversation; to ask a certain question or hear their thoughts or opinions on a certain topic. When there is a warning about death coming closer, it gives families one priceless resource—time. Time to prepare. Time to be intentional. Time to capture. Time to express. Time to sow into the future.

Like the proverb: 'Blessed are those who plant trees under whose shade they will never sit.' There is a window of time to pour into your family's future moments, and those moments will become priceless treasures to your family members.

So what does this look like?

It is recording things about who you are could including memories or personal stories, as well as favourite things, hobbies, and preferences.

This could be captured in:

- Letters
- A book
- Scrapbook
- Video recordings
- Diary or journal
- Blog or vlog
- Private website
- Email account
- Social media account
- Legacy book (with question prompts)

It could be accompanied by a gift for certain milestones:

- Birthdays, graduation, getting their car licence, wedding, etc.

This may seem trivial, but children, in particular, find value and connection in knowing these things about you.

It could be beliefs, opinions, wisdom, or advice around life lessons:

- Wishes and hopes for your family's future
- Areas of praise, appreciation, or encouragement
- Words of comfort

It could also be medical history or information that your children may need in their futures, or things of a practical nature (where to find something).

It could be something targeted for a certain date, event, or occurrence, such as:

- 'Open on a hard or sad day.'
- 'Open on the day the kids are driving you crazy.'
- 'Open on the day you graduate high school.'
- 'Open on the day you get your licence.'

It can be as creative or as simple as you like.

It is an emotionally hard gift to give, but it is a gift that cannot be measured in worth, for your children, spouse or partner, or even your parents or siblings.

# IMPORTANT NUMBERS RECORD



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

CONTACT	DETAILS		DATE
Organ or Tissue Donor Registry			
Office of the State Coroner			
State Mortuary/Bereavement Viewing Facility			
Lawyer			
Funeral Home/Director Funeral Policy #			
Life Insurance Policy #			
Superannuation Policy #			
Australian Death Notification Service. Can notify organisations about the death.			
Bank Acc # Bank (if more than 1) Acc #			
Centrelink / Child Support / Medicare: Advice of Death Form Can be accessed through MyGov			
Births, Deaths & Marriages Registry: (Funeral Director will usually register death)			
Legal Aid (Mortgage Hardship Service)			
Department of Transport: Registration:			
Private Health Insurance Fund Membership #			
Electricity/Synerg Account #			

CONTACT	DETAILS		DATE
<b>Electricity/Synergy Account #</b>			
<b>Gas Account #</b>			
<b>Water Account #</b>			
<b>Internet/NBN</b>			
<b>Phone/Mobile</b>			
<b>Insurance: Car Policy # House Policy #</b>			
<b>Australian Tax Office TFN</b>			
<b>Tax Agent/Agency Or Financial Advisor</b>			
<b>Electoral Commission</b> <i>You do not need to notify the AEC when a relative or friend has died. Information regarding a person who is deceased is provided to the AEC by relevant Births, Deaths and Marriages registries. You may, however, notify the AEC by completing the online form (see link provided).</i>			
<b>Australian Post Free 12mth redirection service</b>			
<b>Local Council</b>			
<b>Current Employer</b>			
<b>Previous Employer If relevant</b>			
<b>Any Business Costs (ABN, Registrations, Licences, Insurance, Software Platforms, Memberships- if relevant)</b>			
<b>Any Educational (Tafe, University, Collages, Children's school/Daycare, etc)</b>			
<b>Any Donations or Direct Debits (Charities, Non for Profits)</b>			
<b>Any ongoing Subscriptions In App subscriptions (exercise, blog, YouTube) Spotify, Netflix, Audible, Software (Office)</b>			

## DIGITAL DEVICES AND ONLINE ACCOUNTS

	LOGIN	PASSWORD
Email Account		
Email Account		
Email Account		
Computer		
Table / iPad		
Phone		
Cloud Storage		
Online Drive		
Facebook Messenger		
Instagram		
Pinterest		
WhatsApp		
Other Social Media		
Office / Google etc.		

## APPS / PLATFORMS

Bank Account		
Health Fund		
Health & Fitness		
Photo Keeping / Storage		
Kindle / Amazon		
Mobile Phone		
Professional / Business		

## IMPORTANT NUMBERS AND HELPLINES

### CRISIS

<b>Lifeline</b>	<b>Call 13 11 14 Text 0477 131 114</b> <a href="http://www.lifeline.org.au">www.lifeline.org.au</a>
<b>Suicide Call Back Service</b>	<b>1300 659 467</b> <a href="http://www.suicidecallbackservice.org.au">www.suicidecallbackservice.org.au</a>
<b>Samaritans Crisis Line</b>	<b>08 9388 2500</b> ( <i>Youth</i> ) <b>08 9381 5555</b> ( <i>Adult</i> ) <b>1800 198 313</b> ( <i>Country toll free</i> ) <b>0863 839 850</b> ( <i>Anonymous Emotional Support</i> ) <a href="http://www.thesamaritans.org.au">www.thesamaritans.org.au</a>
<b>Mental Health Emergency Response Line</b>	<b>08 9224 8888 1300 555 788</b> ( <i>Perth</i> ) <b>1800 676 822</b> ( <i>Peel region</i> ) <a href="http://www.emhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health/Inpatient-and-Other-Services/MHERL">www.emhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health/Inpatient-and-Other-Services/MHERL</a>
<b>Rurallink</b> <i>after-hours telephone service for people in rural and regional Western Australia experiencing a mental health crisis</i> <b>4.30pm – 8.30am weeknights</b> <b>24 hours on weekends and public holidays</b>	<b>1800 552 002</b> ( <i>rural and regional Western Australia</i> ) <a href="http://www.emhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health/Inpatient-and-Other-Services/Rurallink">www.emhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health/Inpatient-and-Other-Services/Rurallink</a>

### FAMILY

<b>Kids Help Line</b>	<b>1800 551 800</b> <a href="http://www.kidshelpline.com.au">www.kidshelpline.com.au</a>
<b>Parenting Helpline</b>	<b>08 9272 1466</b> <b>1800 654 432</b>
<b>Family Helpline</b>	<b>1800 050 321</b> <a href="http://www.familyrelationships.gov.au">www.familyrelationships.gov.au</a>
<b>Relationships Australia</b>	<b>1800 050 321</b> <a href="http://www.familyrelationships.gov.au">www.familyrelationships.gov.au</a>
<b>Maggie Dent Resilience &amp; Parenting</b>	<a href="http://www.maggiedent.com">www.maggiedent.com</a>

## GRIEF

<b>Murdoch Community Hospice St John of God Murdoch Hospital</b>	<b>08 9366 1111</b>
<b>Bethesda Hospice</b>	<b>08 9340 6300</b>
<b>Glengarry Hospital Palliative Care Clinical Nurse Manager</b>	<b>08 9246 6395</b>
<b>Busselton Hospice Care</b>	<b>08 9751 1642</b>
<b>Bereavement Care Centre (NCCG)</b>	<b>1300 654 556</b>
<b>SANDS (Miscarriage, still birth &amp; newborn death support)</b>	<b>1300 308 307 (24/7 phone support)</b> <b><a href="http://www.sands.org.au">www.sands.org.au</a></b>
<b>Names in the Sand/Seashore of Remembrance</b>	<b><a href="http://theseashoreofremembrance.blogspot.com/">http://theseashoreofremembrance.blogspot.com/</a></b>
<b>ARBOR Active Response Bereavement Outreach</b>	<b>1300 11 44 46</b>
<b>Road Trauma Support</b>	<b>1300 004 814</b>
<b>Carer's Counselling Line</b>	<b>1800 007 332</b>
<b>Palliative Care WA</b>	<b>1300 551 704</b>
<b>Solace</b>	<b>08 9474 3297</b> <b><a href="http://www.solacegriefsupportwa.org.au">www.solacegriefsupportwa.org.au</a></b>
<b>Coronial Counselling Service</b>	<b>08 9425 2900 (Perth)</b> <b>1800 671 994 (Regional)</b>
<b>Griefline</b>	<b>1300 845 745</b> <b><a href="http://www.griefline.org.au">www.griefline.org.au</a></b>
<b>Grief Centre of WA</b>	<b>08 9444 7659</b>
<b>The Compassionate Friends</b>	<b>08 9535 7761 (Mandurah)</b> <b>1300 064 068 (24hr National Helpline)</b> <b><a href="http://www.tcfa.org.au/wa-mandurah/">www.tcfa.org.au/wa-mandurah/</a></b>
<b>Silverchain</b>	<b>08 9242 0242</b>



## CANCER

Cancer Council	13 11 20
Redkite CanTeen	1800 733 548
Counselling	1800 835 932
Leukemia Foundation	1800 620 420
Cancer Support WA	08 9384 3544 (Solaris Cottesloe) 08 6383 3475 (Solaris Sir Charles Gairdner Hospital) (08) 9791 1559 (Solaris South West) 0484 244 526 (Solaris Pilbara & Port Hedland)

## HEALTH

Beyond Blue	1300 224 636
Health Direct Mensline	1800 022 222
Australia	1300 789 978
SARC Sexual Assault Resource Centre	08 6458 1828 1800 199 888
WA Alcohol & Drug Service	08 9442 5000 (Perth) 1800 198 024 (Regional) 1800 250 015 (National)
Centrecare	08 9325 6644

## CHILDREN & YOUTH

NCCG "A Friend's Place" National Centre for Childhood Grief	1300 654 556 <a href="http://www.childhoodgrief.org.au">www.childhoodgrief.org.au</a>
Headspace Ages 12 to 26yrs	1800 650 890 <a href="http://www.headspace.org.au/headspace-centres/">www.headspace.org.au/headspace-centres/</a>
Reachout	<a href="http://au.reachout.com">http://au.reachout.com</a>
CanTeen Counselling	1800 835 932
Wombat's Wish VIC	03 9069 0314 0499 966 228 <a href="http://www.wombatswish.org.au">www.wombatswish.org.au</a>
Headspace Ages 12 to 26yrs	1800 650 890 <a href="http://www.headspace.org.au/headspace-centres/">www.headspace.org.au/headspace-centres/</a>
Reachout	<a href="http://au.reachout.com">http://au.reachout.com</a>

## IMPORTANT NUMBERS AND HELPLINES

### INTERNATIONAL

<b>Child Bereavement UK</b>	<a href="http://www.childbereavementuk.org">www.childbereavementuk.org</a>
<b>Cure Bereavement Care UK</b>	<a href="http://www.cruse.org.uk">www.cruse.org.uk</a>
<b>Survivors of Bereavement by Suicide UK</b>	<a href="http://www.uksobs.org">www.uksobs.org</a>
<b>Winston's Wish UK</b>	<a href="http://www.winstonwish.org">www.winstonwish.org</a>
<b>Association for Death Education &amp; Counselling (ADEC) USA</b>	<a href="http://www.adec.org">www.adec.org</a>
<b>Mesothelioma USA</b>	<a href="http://www.mesothelioma.com">www.mesothelioma.com</a>
<b>Comfort Zone Camp USA</b>	<a href="http://www.comfortzonecamp.org">www.comfortzonecamp.org</a>
<b>The Dougy Centre USA</b>	<a href="http://www.dougy.org">www.dougy.org</a>
<b>Web Healing USA</b>	<a href="http://www.webhealing.com">www.webhealing.com</a>
<b>Compassionate Friends USA</b>	<a href="http://www.compassionatefriends.org">www.compassionatefriends.org</a>
<b>Canadian Cancer Society USA</b>	<a href="http://www.cancer.ca">www.cancer.ca</a>
<b>Canadian Virtual Hospice CA</b>	<a href="http://www.virtualhospice.ca">www.virtualhospice.ca</a>
<b>Rainbow: Guiding Kids Through Life's Storm CA</b> <i>Please check and pick which website is the correct one.</i>	<a href="http://www.rainbows.org">www.rainbows.org</a> <a href="http://www.sylvanlakecommunitypartners.ca/post/rainbows-guiding-kids-through-life-s-storms">www.sylvanlakecommunitypartners.ca/post/rainbows-guiding-kids-through-life-s-storms</a>
<b>Skylight NZ</b>	<a href="http://www.skylight.org.nz">www.skylight.org.nz</a>
<b>Canteen NZ</b>	<a href="http://www.canteen.org.nz">www.canteen.org.nz</a>
<b>Grief Centre NZ</b>	<a href="http://www.griefcentre.org.nz">www.griefcentre.org.nz</a>
<b>Grief Relief NZ</b>	<a href="http://www.griefrelief.co.nz">www.griefrelief.co.nz</a>



**LIONHEART**  
RAW TO ROAR GRIEF PATHWAY

# POST-DEATH CHECKLIST



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## POST-DEATH

### **If your Important Person has died at the hospital or hospice**

- ☐ Let the Nurse/Doctor/Palliative Care Team know.
- ☐ Confirm their awareness of any organ donation directives that may be in place.

### **If your Important Person died at home, contact Emergency Services**

- ☐ Ambulance, GP or the Palliative Care Team.
- ☐ Inform the Ambulance about any organ donation directives over the phone or when they arrive.
- ☐ Decide if you would like to see or spend any time with your Important Person's body at the hospital.

### **Contact family & friends**

- ☐ Request that family and friends do not post anything about the death on social media without your permission.

### **Contact your employer (if relevant) to discuss accessing compassionate leave**

- ☐ Employers often provide two days of leave.
- ☐ Some companies may offer more at their own discretion, make sure to check if this is possible for you.
- ☐ Contact your Important Person's employer to notify them (if relevant).

### **Contact Lawyers**

- ☐ Contact your lawyer or the executor of the Will and Estate to see if there were any directives that were relevant for the funeral.
- ☐ Book a meeting time with them for after the funeral to discuss the Will and Estate

### **If your important person died overseas**

- ☐ Contact the Australian Consular Services (in Canberra) for advice and support.
- ☐ If they had travel insurance, call their insurance company on their 24-hour helpline.
- ☐ Be aware of Australian Border Force and their strict quarantine requirements for transporting the body of someone who has died.
- ☐ The death is usually registered with the local authorities in the country where the death occurred.
- ☐ Your Funeral Director will be able to access this on your behalf from the country

### **If your important person died while interstate**

- ☐ Your funeral director can work with you around the transportation of your Important Person's body back home.
- ☐ The death will be registered in the state where the death occurred.
- ☐ The funeral director can help you receive the death certificate.

## STARTING FUNERAL PREPARATIONS

### **Once you've found a Funeral Director**

- ☐ Contact the funeral director of your choice, and book a meeting time to discuss ongoing arrangements.
- ☐ Take a family member or a friend to the meeting with you for support and for them to take notes of the discussion for later reference.
- ☐ Bring funeral insurance/cover, a Will with funeral wishes or directives, etc., to the meeting.

### **Decisions to be made at the meeting include:**

- ☐ To have a viewing or not to have a viewing? (on the funeral day or before)
- ☐ For your Important Person to be buried in a coffin or to be cremated?
- ☐ What you would like your Important Person to wear; would you like them to have make-up on; or any jewellery?
- ☐ What music you would like; would you like a slideshow? Who will speak or give the eulogy?
- ☐ Will there be a dress code? (black/dark or colourful/bright)
- ☐ Do you want a minister or religious advisor to speak?
- ☐ Would you like a wake afterwards; if so, at their premises and catered by them, etc.?

# POST-DEATH CHECKLIST



**LION  
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RAW TO ROAR  
GRIEF PATHWAY

## CONFIRMING FUNERAL ARRANGEMENTS

### After the meeting with the Funeral Director:

- ☐ Finalise the date for the funeral so planning can start.
- ☐ Consider your budget. Funerals can cost from \$4,000 up to \$15,000.
- ☐ Check whether your super funds, insurance, or banks will cover part of the funeral cost.
- ☐ If children are attending the funeral, prepare them for what the plan for the service is and what it will involve, including who will be there, who will speak, whether there will be a slideshow, if you will be speaking, and that people may cry and be sad, etc.
- ☐ If there is a viewing, prepare the children for what to expect when seeing their Important Person's body. Let them know that their body will be cold because their blood has stopped moving around their body, that they won't move, talk, or smile, and that their eyes will be closed, etc.
- ☐ Ask for help with planning the funeral from friends and family who can provide support during this time.

## POST FUNERAL

### Follow up with lawyer or public trustee about the Will & meeting time

- ☐ Determine whether probate or letters of administration are needed. Examine the Will and notify beneficiaries.
- ☐ If your Important Person nominated a beneficiary around leaving a financial gift, follow up with them.

### Contact Centrelink regarding bereavement payments/support/parenting payment.

- ☐ It is income tested & dependent on previous Centrelink payments.

### Contact banks to notify them of the death.

- ☐ Especially if joint accounts or individual accounts are held in their name.

### If there is concern about mortgage repayments, speak to the bank about possible options going forward.

- ☐ Some banks do have internal policies around this.
- ☐ Example: CBA has a Compassionate Care Cove built into mortgages from 2020 that covers 12 months of repayments if a spouse has died on a joint mortgage.
- ☐ Legal Aid WA also has a free service, Mortgage Hardship Service, which can advocate on your behalf.
- ☐ Contact and notify your financial planner or advisor (if relevant).
- ☐ When notifying organisations, some will require a death certificate.

### A death certificate can only be applied for once the death has been registered with the Department of Birth, Deaths, and Marriages.

- ☐ The funeral director will usually be the one who registers the death for you within 14 days from the funeral service; however, you can register the death yourself.
- ☐ A death certificate can be applied for online and will usually cost around \$55, and will be posted either to the funeral director to pass on to you or to you directly.
- ☐ Once a death certificate is received, it can be helpful to make some certified copies of it.

# POST-DEATH CHECKLIST



**LION  
HEART**  
RAW TO ROAR  
GRIEF PATHWAY

## KEY CONTACTS TO NOTIFY

### Superannuation Funds

- ☐ Put in claims or close down the fund
- ☐ Especially if there are Life Insurance policies that are held by your Important Person

### Other Insurance

- ☐ Car, House, Health, Real Estate/Landlord (if relevant)

### Australian Tax Office and Tax Agent

- ☐ You will also need to complete a final tax return lodgement after their death.

### Department of Transport

- ☐ Cancel Licences, registration, or change ownership of vehicles

### State Titles Registry (if relevant)

- ☐ Regarding land titles/deeds

### Local Council

- ☐ Regarding Rates & Water (if relevant)

### Electoral Commission

- ☐ To remove from the electoral roll

### Education Providers (if relevant)

- ☐ Universities, Colleges, TAFEs, children's primary/high school

### Australian Post to redirect mail

- ☐ They have a free 12-month redirection service

### Professional Affiliations

- ☐ Professional memberships, registrations, insurances, licences, software platforms, etc.

### Contact Utilities

- ☐ Electricity (Synergy), Water Corporation & Gas provider

### Cancel the following:

- ☐ Community Groups: Library, gym, sporting clubs, theatre, art, etc.
- ☐ Australian business registration ABN (if relevant)
- ☐ Phone & internet providers, subscriptions OR change the account to your name
- ☐ Pay TV, Spotify, Audible, Software (Office, Photos, etc.)
- ☐ Health care and concession cards (if relevant)
- ☐ Ongoing donations or direct debits to charities or not-for-profits (if relevant)
- ☐ Request removal from any marketing/advertising mailing lists

### MyGov Account

- ☐ Make sure Centrelink, Medicare, Child Support (if relevant) have been notified, then close down and delete

### Social Media Accounts

- ☐ Close, archive, or memorialise: Facebook, Instagram, X, SnapChat, TikTok, WhatsApp, Viber, YouTube, Pinterest, LinkedIn

# HOW TO HELP ME IN MY GRIEF

## CHECKLIST OF PRACTICAL HELP

Dear

Thank you for your offer to help. It's tricky for me to know how to ask for help or know which areas I need help in right now. I've ticked the list below with some practical ways you could be most helpful at the moment. I hope this list can help to guide you in how you can best support us.

### Emotional Support

- ☐ Say my Important Person's name
- ☐ Share memories about them
- ☐ Help me plan the funeral
- ☐ Send a message to say you're thinking of me
- ☐ Mark your calendar with important dates
- ☐ Go through photos with me
- ☐ Commit to being there for the long haul
- ☐ Invite me out, but don't push
- ☐ Spend time with me
- ☐ Help me with the hard stuff
- ☐ Write down memories you have of my Important Person so I can keep them

### Financial Support

- ☐ Bring things over (not just flowers or food)
- ☐ Pay for things
- ☐ Buy pet food
- ☐ Help with taxes or banking
- ☐ Pay for a cleaning service
- ☐ Buy some Uber Eats vouchers
- ☐ Buy grocery shopping vouchers
- ☐ Cover school fees/day care costs for a period
- ☐ Cover my energy or gas bill for a quarter
- ☐ Take the kids shopping

### Domestic/Home Support

- ☐ Organise a meal train or roster
- ☐ Do the laundry
- ☐ Mow the lawn
- ☐ Clean the toilets
- ☐ Do the dishes
- ☐ Do some food prep
- ☐ Vacuum
- ☐ Mop
- ☐ Water the plants or do some weeding
- ☐ Clean the car
- ☐ Throw out dead flowers
- ☐ Move furniture
- ☐ Change lightbulbs or do some general maintenance around the house

### Nurture & Care

- ☐ Let me take a nap
- ☐ Bring me a care package or pamper pack
- ☐ Get me a massage voucher
- ☐ Bring me a journal or art supplies
- ☐ Get me bookstore or amazon voucher
- ☐ Bring the kids a soft toy or art/craft supplies

### Day to Day Support

- ☐ Take the kids to school / park / sport
- ☐ Decorate for Christmas
- ☐ Help me write thank you notes
- ☐ Fill out paperwork
- ☐ Call and notify people or organisations
- ☐ Babysit
- ☐ Run errands
- ☐ Help with back to school preparation
- ☐ Walk the dog





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- ☐ Run errands
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- ☐ Walk the dog





# What Bereaved Children Want to Know About Death and Grief

Caitlin Joy<sup>1</sup> · Lexy Staniland<sup>2</sup> · Trevor G. Mazzucchelli<sup>1</sup> · Shelly Skinner<sup>3,4</sup> · Lisa Cuddeford<sup>4</sup> · Lauren J. Breen<sup>1,2</sup>

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## Abstract

While childhood bereavement is common, children's bereavement needs are not well understood. It is recognized that children's understandings of death fundamentally differ from those of adults, however, limited research has explored this from a child's perspective. Insight about children's understandings and needs can be drawn from the questions they ask about it. Bereaved children aged 5–12 years were invited to submit questions about death and grief during a camp for grieving children. Children's questions ( $N = 213$ ) from 10 camps were analyzed using conventional content analysis. Five themes were identified: *Causes and Processes of Death*; *Human Intervention*; *Managing Grief*; *The Meaning of Life and Death*; and *After Death*. Children's questions revealed that they are curious about various biological, emotional, and existential experiences and concepts, demonstrating complex and multi-faceted considerations of death and its subsequent impact on their lives. Findings suggest that bereaved children may benefit from opportunities to freely discuss their thoughts about death, which may facilitate appropriate education and emotional support.

**Keywords** Bereaved children · Grief · Death · Children's understanding · Children's questions

## Highlights

- Content analysis of 213 questions asked by bereaved children aged between 5 and 12 years resulted in five themes: Causes and Processes of Death, Human Intervention, Managing Grief, The Meaning of Life and Death, and After Death.
- Bereaved children ask meaningful questions about death and grief and are curious about biological, emotional, and existential experiences and concepts.
- Bereaved children may benefit from support that offers opportunities to ask questions alongside basic death and grief education, and strategies for emotion regulation.

Bereavement in childhood is common, with 5–7% of children in Western countries experiencing the death of a parent and/or sibling before age 18 (Australian Bureau of Statistics, 2010; Burns et al., 2020; Parsons, 2011). When including the loss of other close family members and friends, over 50% of children have been bereaved (Harrison

& Harrington, 2001; Paul & Vaswani, 2020). Of emerging concern is the effect of COVID-19, with an estimated 1.1 million children globally experiencing the death of a parent in the first 14 months of the pandemic (Hillis et al., 2021). The prevalence of childhood bereavement highlights the need for effective and appropriate support, particularly considering the potential for adverse outcomes following the loss of a close person. While grief reactions such as sadness are understandably common, childhood bereavement is associated with anxiety and depression, poor academic performance, suicidality, and the development of affective, psychotic, and substance use disorders (Burrell et al., 2018; Elsner et al., 2022; McKay et al., 2021; Simbi et al., 2020; Syer et al., 2021; Weinstock et al., 2021). Mitigating these impacts requires bereavement support for children that considers their unique understandings of death and experiences of grief.

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Children's understandings of death and dying are typically conceptualized within the biologically rooted death concepts of inevitability, universality, irreversibility, cessation, and causality (Hoffman & Strauss, 1985; Panagiotaki et al., 2018). Generally, children demonstrate formative understandings of death by age three, develop comprehension of some death concepts by age six, and reach a more complete understanding of death by age 10 (D'Antonio, 2011; Harris, 2018; Kentor & Kaplow, 2020; Panagiotaki et al., 2018). This evolving understanding is largely viewed as a function of cognitive and emotional development (McCoyd et al., 2021, p. 5); however, limited research explores death concepts from the child's perspective (Ahmadi et al., 2019).

Insight about children's understandings of death can be drawn from the questions they ask about it. The process of asking questions and receiving answers is key to making sense of death (Menendez et al., 2020). As reported by caregivers, children commonly ask, "Why do people die?", "Will I die?", and "Will you die?" demonstrating a developing understanding of the inevitability and universality of death (Gutiérrez et al., 2014; Renaud et al., 2015). Questions children ask about death may also offer insight into their bereavement needs. Martinčeková et al. (2020) asked adults who were bereaved as children to describe how they could have been better supported to cope with their loss. A key theme was the need for more information about death and grief, suggesting that children desire conversations about death and grief when they are bereaved. However, retrospective accounts of childhood bereavement are inevitably colored by adult cognitions and emotions, limiting the utility of these accounts to provide genuine insight into children's bereavement needs.

Children largely rely on their caregivers to offer bereavement support and provide information about death (Menendez et al., 2020; Scott et al., 2019), and evidence suggests that children who receive this support and information cope better than those who are shielded from discussions about death and grief (Martinčeková et al., 2020). Yet adults are often reluctant to discuss death and dying with children (Fearnley, 2010; Hunter & Smith, 2008) and tend to underestimate children's ability to comprehend death concepts (Gaab et al., 2013). By understanding the questions bereaved children have about death and grief, and centering their unique needs and experiences, caregivers may be better equipped to support bereaved children effectively and appropriately.

## The Present Study

The present study aimed to better understand children's bereavement needs by examining questions posed by bereaved children participating in a bereavement service. While previous

research has investigated this retrospectively, few studies have sought to hear from bereaved children directly, meaning their needs may not be wholly understood or met. To address this gap, we invited bereaved children to ask questions about death and grief and used the resulting data to answer our research question: What do bereaved children want to know about death and dying?

## Method

### Lionheart Camp for Kids

Lionheart Camp for Kids (LCK) is a free day-camp that offers bereavement support to grieving children aged 5–17 years and their families (Griffiths et al., 2022). Based in Western Australia, LCK runs several times per year across two consecutive days where trained professionals and volunteers deliver grief psychoeducation to children and their caregivers through a series of developmentally appropriate activities. Caregivers can learn about the service through various avenues, including hospitals, schools, social media, and the LCK website (<https://lionheartcampforkids.com.au/>). As the service is designed to support grieving children and their families, only bereaved children are eligible to participate, however, there are no eligibility requirements related to grief symptoms. Children must be accompanied by their caregiver for the duration of the camp, and caregivers are expected to actively participate in camp activities.

On the first day of camp, facilitators normalize participants' experiences by inviting them to share about their deceased family member before working through a series of structured activities (e.g., creating memory rocks) interspersed with breaks and free play. Children are also introduced to a centrally located question box on the first day and invited to anonymously submit questions about death and grief that are answered by a guest medical doctor the next day. Facilitators reassure the children that all questions are valid and will be answered. Children are encouraged to use the question box any time they have a question. If children have writing difficulty, facilitators write the child's question verbatim, clarifying the meaning of a word only when necessary. On the second day, participants learn different coping strategies (e.g., grounding, breathing), caregivers are provided psychoeducation about child development and grief, and collaborative activities between children and adults are facilitated to encourage processing and meaning making.

### Procedure

Ethical approval was granted by Curtin University's Human Research Ethics Committee (approval number HRE2020-

**Table 1** Example Coding Process

Data	Meaning Unit	Code	Category	Theme
There should be more people caring about people who died	People caring	Caring	Helping people who are dying	Human intervention
What's the point of life if you die?	Point of life if you die	Meaning of life	Meaning of life	The meaning of life and death
If my dad died of cancer, does that mean I will die of that too?	Dad died of cancer, will I die of that too	Hereditary conditions	Understanding a condition	Causes and processes of death
Why do you sometimes feel jealous of other people who have not had other people in their family die?	Jealousy of others who are not bereaved	Comparison with others	Social impacts of loss	Managing grief
Is cancer contagious?	Cancer, contagious	Contagion	Understanding a condition	Causes and processes of death
How does it feel to die?	How, feel, die	How does dying feel	Biology of death	The meaning of life and death
If daddy comes back	Deceased comes back	Deceased returning	Reincarnation	After death

0560). There was no formal assent process for children; however, families provided written informed consent to have any photos, videos, or activity data collected during the camp used for program promotion or evaluation research. Children's questions from 10 camps run between July 2017 and April 2021 were collated and comprise the data for this study.

## Participants

Participants were approximately 220 bereaved children who attended one of the 10 LCK camps included in the study. Children were aged between 5 and 12 years, with the mean age ranging from 7.4 years in 2017 to 8.7 years in 2021. There was an approximately even split of boys and girls. Most children were developmental typical, with several identified by their caregiver as having ADHD, Autism, or a sensory processing disorder. Most participants resided in Perth, Australia, with one camp for residents of Western Australia's Southwest region. All children had experienced the death of a parent, sibling, or other family member (e.g., uncle, grandmother). Time since death ranged from four months to five years, with most losses occurring within the 12 months prior to attending the camp. Causes of death included cancer, road traffic crash, heart attack, suicide, workplace accident, substance use, and childhood illness. To maintain children's anonymity, no demographic data were collected alongside the questions submitted by participants.

## Data Analysis

Due to the limited literature available about children's questions about death and grief, a conventional content analysis was used to analyze the data (Hsieh & Shannon, 2005). This approach is suitable for describing a phenomenon (i.e., children's questions about death and grief) and allows data to be coded inductively, with categories formed from the data itself, rather than from predetermined coding structures or theories (Hsieh & Shannon, 2005). The steps outlined by Hsieh and Shannon (2005) were followed. First, data were read for familiarity and immersion before being condensed into units of meaning. Codes were then iteratively derived by identifying words that captured discrete concepts. These codes were then sorted into categories. Relationships between categories were used to cluster codes into themes. See Table 1 for an example of the coding process.

## Quality Criteria

The trustworthiness of the present study was supported through several quality criteria. First, the research was

conducted by a multi-disciplinary team spanning psychology, social work, and medicine, with members bringing expertise in children's development, parenting, grief and loss, and qualitative research. Second, dependability of the analysis and subsequent findings were supported through blind coding of all data by a second coder indicating satisfactory coding agreement, Cohen's  $\kappa = 0.78$  (Kyngäs et al., 2020). Reporting data quotes in their original state, including spelling and grammatical errors, supported confirmability, and credibility was supported through a detailed audit trail documenting analytic processes and decisions.

## Findings

A total of 213 questions were submitted by children across the 10 camps. Twenty-three questions unrelated to the present study (e.g., questions about camp staff) were excluded. Five themes were determined from the remaining 190 questions: Causes and Processes of Death, Human Intervention, Managing Grief, The Meaning of Life and Death, and After Death (Table 2).

### Causes and Processes of Death

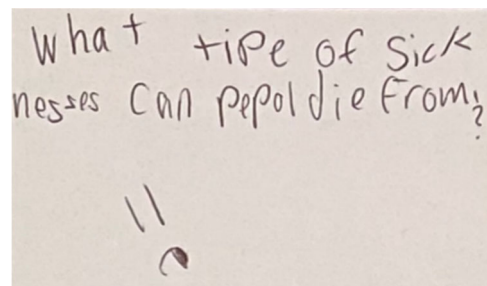
Causes and Processes of Death was the most prominent category within the data and captured children's curiosities and concerns regarding why and how people die. Children asked, *"What tipe of sicknesses can pepol die from?"* (Fig. 1) and *"Have doctors found out how babys die?"*, demonstrating a desire to understand what causes death. Regarding processes of death, children asked, *"How does the body actually die?"* and *"Why do people die so fast?"*. Children also asked about animal death, *"How can animals die?"*, suggesting children want to understand death processes in other living beings.

Children queried if certain conditions were contagious, *"Is cancer contagious?"* or hereditary, *"If my dad died of cancer, does that mean I will die of that too?"* and whether causes of death could come from animals, *"Can humans get diseases from animals?"*. These questions suggest children want to better understand various manners of death. Children also sought to understand the experience of death and dying, *"How does it feel to die?"* and *"Does it hurt when you die?"* Such questions demonstrate children's consideration of how others might die. This was further exemplified in questions such as, *"When will I die?"*, and *"How do I know when I'm dying?"*, suggesting that children consider their own death and want to better understand how and when this might occur.

Children's questions appeared to draw on their existing understandings and experiences. For example, one child asked, *"Do people's hearts shut down?"*, reflecting

**Table 2** Frequency of Themes and Categories

Theme	Category	Frequency
Causes and process of death		77
	Understanding a condition	40
	Understanding the human body	17
	Biology of death	18
Managing grief	Animal death	2
		43
	Social impacts of loss	16
	Interpretations of death	5
Human intervention	Grieving processes	14
	Understanding emotions and coping	8
		33
	Helping people who are dying	10
The meaning of life and death	Preventing death	8
	Understanding suicide	9
	Understanding substance use	6
		19
After death	Meaning of life	3
	Who lives and dies	5
	Meaning of death	9
	Meaning of suffering	2
		18
	Reincarnation	2
	Life after death	5
	Contact with the deceased	3
	Understanding heaven	8



**Fig. 1** Question Relating to The Biology of Death and Dying

some understanding of the heart's function in keeping the body alive. Another child asked, *"If someone is on life support and are all of their organs still working?"*, which may reflect the child's attempt to understand the death of someone they knew. Suicide and substance use were also referenced in some children's questions, likely reflecting their loved one's cause of death. Regarding suicide, children asked, *"Why do people kill themselves?"* and



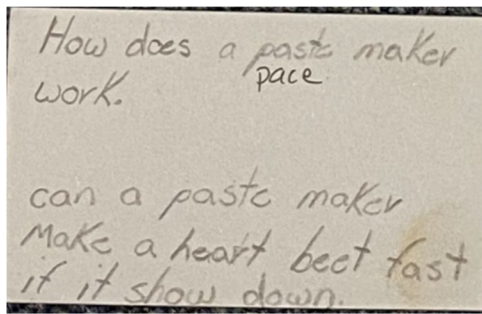


Fig. 2 Question Relating to Human Intervention

"What is depression? Why do people kill themselves because of it?". In relation to substance use, questions asked were "Why do people get addiction? Why do they choose to do their addiction?", "How do you get drunk?" and "Why would someone want to do drugs?". Such questions demonstrate that children recognize and want to understand the factors that may contribute to suicide and substance use.

### Human Intervention

Human Intervention captures questions related to preventing death and helping people who are dying. Children asked about specific technologies, such as pacemakers, "How does a paste maker work? Can a paste maker make a heart beet fast if it show down?" (Fig. 2) and treatments, "Is there a medicine that can stop cancer?", "How can you cure heart cancer?" and, "If you have brain cancer, how many medicines will you have?". A desire to understand contexts of death was also demonstrated, "Does everyone who goes to hospital die?". Children's questions suggest they want to know how death can be prevented or delayed.

Preventing future deaths was a concern for children who asked, "How can I protect my family from other people dying?" and "How can I cope without medication?". These considerations may reflect children's internalization of responsibility for their own and others' death. Indeed, questions reflected children's desire to help those who are dying, "Who can you we save people live or know to call 000 [the emergency number in Australia]?" and, "How to be a doctor or nurse?". Children demonstrated varying levels of understanding of medical interventions, with some questions reflecting a desire to understand the purpose of such interventions, "Why do you help people when they're dying?", while others reflected concern with why help is not always offered, "Why don't they always try to resuscitate people?". Children wanted to better understand how people who are dying are medically supported, "How do doctors help?", "Why do doctors give people tablets that can cause trouble?" and, "When people are close to dying, do they give them a needle/medicine?". These questions suggest

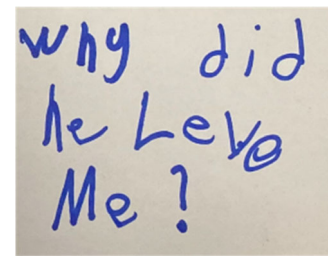


Fig. 3 Question Relating to Becoming Bereaved

that knowledge of medical interventions is important to children's understanding of death.

### Managing Grief

Becoming Bereaved reflects children's efforts to make sense of death and their subsequent social and emotional experiences. Questions such as "Why did he leve me?" (Fig. 3) and "Is it my fault?" suggest that children seek to understand death in relation to themselves and may perceive the death of a loved one as their responsibility. This was evidenced in one child's question, "Did me having a cold when my dad had cancer and his immune system was low cause him to die?". While this question suggests egocentric thinking (Hunter & Smith, 2008), it may also reflect a desire to understand death in a way that feels controllable. Similarly, another child asked, "People say it's my fault dad killed himself, what do I do to make sure no one else kills themselves because of me?" Clearly, communication with children about death, and the reasons for it, is critical to avoid unnecessary pain caused by internalizing responsibility. Indeed, this was reflected in the questions, "I don't think it's fair people don't tell kids the truth?" and "Why didn't the doctors tell me dad was going to die?"

Children asked many questions about their experiences following bereavement, seeking to understand confusing emotional and physical responses. They sought to understand their emotions, with questions such as, "Why do I feel sometimes happy and sad at the same time?" and "Why am I more sad than my brother? Did he love mum less than me?". Children also sought to understand physical responses such as changes to their sleep, "Why do I sleep all the time?" and "Why can't I sleep at night?", and physical sensations, "Body feels constant pains. Chest pains etc. What is this?" and "Why do people cry?". These questions may reflect children's limited understanding of how emotions manifest physically. Children's questions also reflected a desire to understand the purpose of their emotions, "Why do we have to deal with grief?", and how to manage them, "How can I deal with someone dying?", "How do you not miss them?", and "How can you handle your big



feelings". Children's difficulty coping with grief was evidenced in questions such as, *"How do I hurt myself without people knowing instead of overheating and burning myself?"*. Emotion regulation skills are evidently an important aspect of bereavement support for children.

Questions relating to children's social world were evident. Some children reflected concerns about their security, *"What will happen to me if my mum dies too?"*, and others sought assistance with gaining support, *"Can someone help my teacher, she doesn't understand?"*. These questions demonstrate children's future-oriented thinking and considerations of how their life has and may be impacted by bereavement. Social comparisons also appeared relevant to children's understanding of their own grief as they sought to understand changes in their social world, *"Why do kids bully me at school now?"*, and how they relate to others, *"Why do you sometimes feel jealous of other people who have not had other people in their family die?"* and *"How do I come across normal to other people?"*. Children are evidently alert to how they are perceived, which may represent an additional source of stress accompanying the existing pain of loss.

### The Meaning of Death

The meaning of death captures children's questions about life's purpose and why people die. Questions such as, *"What is the meaning of life?"* (Fig. 4) and *"What is the point of living if you just have to die?"* demonstrate children's existential considerations.

Such considerations were further evidenced in complex questions such as, *"If kids don't have a dad, why would god let their mum die?"*, *"Why do people have to die at 50 and under?"* and, *"How did my nana and granddad live for that much years? But mum died young?"*. These questions reflect pre-existing understandings of life and death that have been called into question as a result of bereavement.

A desire to understand who dies and who lives was apparent in questions such as, *"Why do some sick people get better and some don't?"* and *"Why do doctors make some people better but not others?"*, as was a desire to understand the meaning of death, *"Why do people die?"*, *"Why do baby's die?"* and, *"Why do people have diseases?"*.

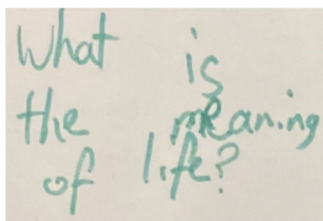


Fig. 4 Question Relating to the Meaning of Life

Children's questions reflect complex thoughts that suggest their understandings of death and dying are multi-faceted and potentially philosophical.

### After Death

The final category, After Death, comprises questions relating to what happens to a person once they have died. Many questions related to continued existence after death, with questions related to how an individual who has died continues to live, *"What do you do when you die?"*, *"Where do we go when we die?"*, *"Can you see people when you're dead?"* and, *"Will my uncle see my pet dog in the afterlife?"* Heaven featured prominently as an after-death destination, with children asking, *"What is heaven?"*, *"Is heaven real?"*, *"Do you go to heaven after you die?"*, *"Can you still love people from heaven?"*, and *"What does it feel like to be in heaven?"* (Fig. 5). This likely reflects a dominant cultural narrative surrounding death.

Children also asked about reincarnation, *"Will my uncle be born again as a human or as an animal?"*, and future interactions with the person who died, *"If daddy comes back..."* and *"Can I still talk to my important person?"*. Such questions demonstrate children's developmental inability to understand the permanency of death and reflect a desire to maintain contact and connection with their lost loved one.

### Discussion

The present research sought to understand what bereaved children want to know about death and grief. Using conventional content analysis, questions about death and grief were collated and analyzed, offering insight into bereaved children's thoughts and feelings. Questions revealed that children are curious about various biological, emotional, and existential experiences and concepts, demonstrating complex and multi-faceted considerations of their loved one's death and its subsequent impact on their lives.

Broadly, children's questions appeared to serve a confirmatory function, with their questions relating to death concepts known to be developing in childhood, such as universality, irreversibility, and inevitability (Hunter & Smith, 2008). Such questions suggest that children actively construct their understanding of death through learning

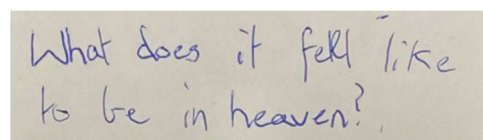


Fig. 5 Question Relating to After Death

processes proposed by Piaget and Vygotsky. Children's questions are attempts at discovery; the death of their loved one causes disequilibrium in their mental model, and they seek to correct this through discovery of new information (Piaget, 1954, pp. 350–379). Further, children rely on others (in this case a doctor) to provide the answers, thereby developing their mental model in a social context (Vygotsky, 1978, p. 24). Children's questions are formed based on existing knowledge, but they seek to explain inconsistencies or newly discovered gaps as a result of bereavement by posing questions to others in their social world.

Children's questions demonstrated varying degrees of understanding and knowledge, likely reflecting differences in age-based cognition. This supports age-based approaches to bereavement supports, though individual differences should be considered. While we are not able to account for the role of age in children's questions due to the anonymous nature of our data collection, the questions children ask about death reflect knowledge within their zone of proximal development (Vygotsky, 1978, p. 84). Regardless of age, individuals work through three stages when learning: (1) what cannot be understood or achieved, even with guidance, (2) what can be understood or achieved with guidance (the zone of proximal development), and (3) what can be understood and achieved independently. This model underpins scaffolding, an approach to education recognizing that individuals require a lot of guidance and support when they are first learning a skill/concept, which is tapered as the individual progresses to mastery. Therefore, the answers given to children's questions about death and grief must be within their scope of understanding, which is informed not just by their biological age, but also their life experiences. A child who has previously been exposed to death is likely to have different questions than a child who is experiencing their first exposure to death, even if they are of the same biological age. Likewise, a child who has not been bereaved is likely to ask different questions compared to a child who has been bereaved. Therefore, children's questions are informed by their experience and reflect their zone of proximal development, informing the question recipient of what may or may not be within the child's scope of understanding.

A preponderance of questions related to biological concepts, with a focus on the causes, processes, and states of death and dying. This is consistent with the literature demonstrating that children's understandings and conceptualizations of death are largely biological (Harris, 2018; Vázquez-Sánchez et al., 2019; Yang & Park, 2017) and supports the recommendation for death education to be integrated into formal curricula across all education levels (McAfee et al., 2022). Children are likely to benefit from death education that incorporates comprehensive

information about the causes and processes of death and dying, with increasingly complex death concepts introduced as their education progresses (McAfee et al., 2022).

Children's questions demonstrated their need to make sense of death. For some children, this learning was grounded in egocentric thinking, as seen in questions like, "*Why did he leave me?*" and "*Is it my fault?*". Perceptions of personal responsibility are common among grieving children (Kentor & Kaplow, 2020) and this finding reflects the importance of discussing death with children. While egocentric thinking tends to dissipate with age, there is potential for such thinking to lead to thoughts of abandonment or responsibility, which can perpetuate distress and foment guilt (Cohen et al., 1977; Raveis et al., 1999). Dispelling such thoughts is important; however, children are aware of adults' tendency to censor death-related information (Paul, 2019) and may be reluctant to ask questions as a result. Due to the anonymous nature of the data collected in the present study, children may have asked questions otherwise kept hidden. Therefore, these findings provide support for open discussions with bereaved children about death.

Metaphysical conceptualizations of death, such as those involving considerations of the afterlife, were common in children's questions, as they sought to make sense of what happens after someone dies. Consistent with other research (Vázquez-Sánchez et al., 2019), heaven was a frequent afterlife concept. This likely reflects dominant Western cultural narratives present in Australia, whereby heaven is often referred to in discussions with children about death (Arruda-Colli et al., 2017; Renaud et al., 2015). While we did not record participants' religious affiliation, Australian Census data shows Christianity to be the most endorsed religion (52.1% of respondents in 2016 and 43.9% of respondents in 2021; Australian Bureau of Statistics, 2022). As such, this offers a potential explanation for the commonality of Christian death concepts such as heaven. Cultural and religious differences among children in the present sample could not be accounted for but are important avenues for further inquiry. Culture and religion have important implications for how adults understand and experience bereavement (e.g., Rosenblatt, 2008, pp. 207–222), which could be the case for children, too.

Consistent with the literature (see Dalton et al., 2019 for a review), children's questions demonstrated a desire to be told their loved one was dying. Children wish to be informed of their loved one's possible/inevitable death and shielding children from such knowledge may be detrimental, leading to tension, distress, and anxiety (Dalton et al., 2019). It is likely that children would benefit from discussions about a loved one's inevitable death, allowing for psychological preparation; however, children are aware of adults' reluctance to discuss death with them, and this serves as a barrier to such discussions (Paul, 2019).

Equipping caregivers with tools and strategies to effectively engage in discussions about death with their children is key to preparing children for the death of a loved one and supporting them after bereavement. Research with adults caring for a close person near death shows that many are not prepared (Breen et al., 2018). Thus, preparing children for bereavement likely means preparing the adults around them, too.

Children's needs after bereavement were evident in the questions they asked about how to cope with and manage difficult emotional experiences, demonstrating their need for emotional support, including co-regulation, validation, and reassurance. Emotion regulation skills are an established need for grieving children (Ahmadi et al., 2019; Scott et al., 2019; Youngblut & Brooten, 2021) but caregivers often struggle to find the best approach. Given the importance of the caregiving environment to children's processing of grief (Alvis et al., 2022), it is critical that caregivers are offered ample support and knowledge to effectively provide safe and supportive environments. Interventions such as Lionheart Camp for Kids (Griffiths et al., 2022) offer a structured and active environment to offer children and their caregivers such supports. Children tend to be exposed to death through media (e.g., books, television, films) or non-human loss (e.g., death of an insect) prior to losing a close person (Renaud et al., 2015; Zedníková & Pechová, 2015), there is opportunity for caregivers to capitalize on the early questions children ask to provide them with a comprehensive understanding and set of coping skills.

## Limitations and Future Directions

While the present study offers important insights into the types of questions bereaved children ask about death and grief, there are several factors that we could not account for. Due to the anonymous nature of the data collection, we were unable to compare questions based on demographic details such as age, sex, race, religion, or culture, which are likely crucial to our understanding of what bereaved children need. Likewise, we were unable to compare questions based on children's relationship with the deceased (e.g., parent compared to sibling), the manner of death (e.g., terminal illness compared to suicide), and time since loss (e.g., one month compared to one year ago). Such information could offer insight into children's needs at varying stages of their bereavement experience and depending on who died and how. Future research on bereaved children's questions should account for these details to strengthen our understanding of what children want to know about death and grief, and improve the bereavement supports designed for them.

The data collection method allowed for children to ask questions anonymously in their own time, a naturalistic approach that may have captured questions from children that could be missed in time-bound and identifiable settings such as an interview or focus group. Despite the potential benefits of this approach, there are several drawbacks to note. First, children with limited writing abilities or verbal expression may not be well-represented in our data. While children who had difficulty writing were assisted by a camp facilitator, this process may have impeded the methodological benefit of anonymity. Second, handwritten notes were decontextualized, meaning ambiguity could not be resolved. Lastly, all notes were interpreted through an adult lens. Children's meanings may be interpreted inaccurately or incompletely due to cognitive and experiential differences.

The lack of identifying information also meant we could not determine with certainty how many questions each child asked. It is possible a small subgroup of children asked lots of questions, rather than the questions representing the broader sample of children. Similarly, while the age range of camp participants was 5–12 years, we cannot know whether the full age range was captured in our data set, which limits the conclusions we can draw about the relevance of the questions to any given age. In future research, data collection could be adapted to include a space for children to record their age alongside their question. This would retain anonymity while giving additional detail to contextualize questions. Generalizability is further limited by the sample. Participants comprised children participating in a single bereavement program located in Western Australia; a more complete understanding of the questions children have about death and grief necessitates multiple-site recruitment and data collection from diverse samples of children.

While the aim of this study was to categorize the questions bereaved children ask about death and grief, the nature of the data means that only a conceptual understanding of children's questions can be gained. In absence of data related to children's lived experiences and the context of their questions, the present research cannot offer a nuanced picture of what children want to know about death and grief. For example, we are unable to determine whether children only asked questions related to the death of their own loved one, or if their questions advanced beyond their direct experience and reflected things they had been exposed to at camp. Given that children hear about each other's bereavement experiences during the camp, their questions may capture not just their own experiences but those of other children as well. Future research might catalog children's questions over time to examine temporal changes in their questions.

Finally, while children's questions reflected current understanding of children's death concepts, it is possible

that the focus on medical and biological aspects emerged because children knew their questions would be answered by a medical doctor. If questions were answered by a different expert (e.g., psychologist, teacher, individual with lived experience), different questions may have been posed. Future research might investigate the effect of different types of experts on children's questions, which may be useful for directing more specific preparation to those involved in the care of bereaved children.

## Practical Implications

The questions bereaved children ask about death and grief can be seen as windows into their cognitive-emotional processing. As such, they may serve as indications of a child's current understandings and be used to direct appropriate and suitable bereavement supports. For example, questions such as *"How can I protect my family and other people from dying?"* and *"Is it my fault?"* indicate a child may be internalizing responsibility for the death of their loved one. This type of question requires a response that reassures the child they are not to blame for the death and that they cannot prevent the death of others, without causing undue fear of death. The information provided to children about death and grief should consider not just what is deemed age-appropriate, but also what is relevant for a child's own level of understanding.

In the present study, children's questions indicated an overarching need for pre-emptive psychosocial education. With many questions related to making sense of physiological, emotional, and social experiences, bereaved children may benefit from explanations of what to expect. For example, children asked about body pains and sleep difficulties, suggesting they need to be taught how grief (and other emotions) can manifest in the body and ways to manage these physiological experiences. Likewise, questions like *"How do you not miss them?"* and *"Why am I more sad than my brother?"* suggests a need for education about emotions, including their purpose and how to cope with them. This kind of education could serve to normalize grief experiences and prepare children for emotions they may otherwise find confusing and distressing.

Additionally, helping children navigate social relationships and school contexts after bereavement may assist with questions such as, *"Why do kids bully me at school now?"* and *"Can someone help my teacher, she doesn't understand?"*. Children may not expect to be treated differently following bereavement; education about how others may act could be beneficial by preparing them for difficult interactions and equipping them with ways to manage such experiences. Being able to answer children's questions requires adults understanding that avoiding the topics of

death and grief is not helpful when children are naturally curious. Adults involved in the care of children need appropriate death literacy (Noonan et al., 2016) and grief literacy (Breen et al., 2022) to feel more comfortable taking about these issues with children.

Integrating death education into school curricula can be an effective approach to pre-emptively supporting children to cope with bereavement. Doing so provides preparatory guidance, which equips children with knowledge, language, and coping strategies that can be drawn upon when a child faces loss (McGuire et al., 2013). Although not currently standard practice in Australian schools (Kennedy et al., 2017), international death education curricula typically incorporate information that facilitates recognition and understanding of grief, language to identify and explain grief, and strategies to cope with grief and related experiences (Dawson et al., 2023; Friesen et al., 2020). In combination with professional development for educators, death education can prepare children and adults to better manage bereavement. For example, when asked, *"Why am I more sad than my brother?"*, an educator can explain that everyone's experiences of grief are different, with reference to concepts discussed during death education lessons. With widespread integration of death education, social issues may also be addressed, reducing the likelihood of bullying and isolation (Stylianou & Zembylas, 2018).

## Conclusion

This study contributes to a growing body of literature focusing on the experiences and perspectives of bereaved children. Through an anonymous method of data collection, we were able to collate and analyze children's questions about death and grief, finding that children are curious about practical, social/relational, and emotional/experiential aspects of death and grief. While children's questions were grouped into five themes, these were underpinned by two core findings. First, children's understanding of death begins with biology, which provides an anchor point from which other death and grief concepts can be built. Second, children require psychosocial education to prepare them for bereavement and equip them with tools and knowledge to understand and manage physiological, emotional, and social bereavement experiences. These findings provide valuable insight into bereaved children's thoughts and curiosities about death and grief and illustrate the importance of adults around them being sufficiently equipped to elicit and answer such questions. Children's bereavement supports may benefit from considering not just what children need to know, but also what children *want* to know about death and grief.



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## Compliance with Ethical Standards

**Conflict of Interest** Lionheart Camp for Kids had no role in the design of the study or in the analysis and interpretation of data.

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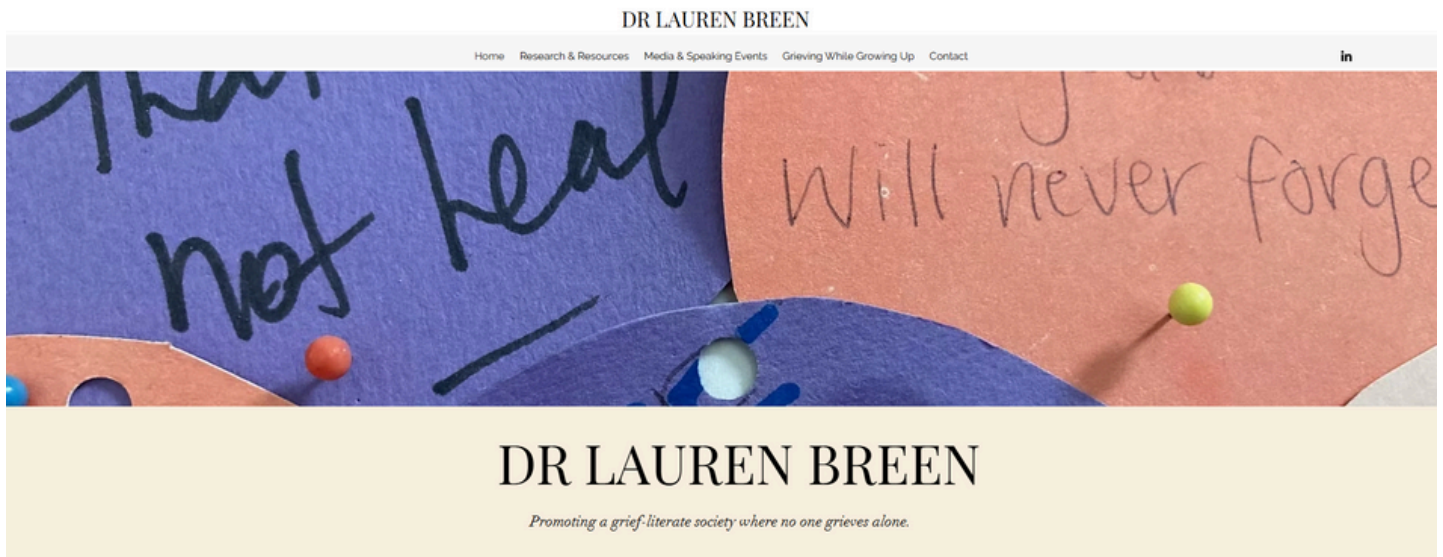
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# Lauren's resources

- Working WITH grieving young people to create a world that better supports them



Lauren's website, with various resources, videos, and infographics:

[www.drlaurenbreen.com](http://www.drlaurenbreen.com)

Good  
grief,  
this  
hurts!

A circular graphic composed of concentric watercolor rings in various shades of blue. The text "Good grief, this hurts!" is written in a white, sans-serif font in the center of the circles.





Curtin University

# ***Working WITH grieving young people to create a world that better supports them***

PROFESSOR LAUREN BREEN (she/her)  
BSc(Hons), GradCertEd, PhD, FAPS, FCCOMP, Registered Psychologist, FT, FHEA

2025

A global university

Western Australia | Colombo | Dubai | Malaysia | Mauritius | Singapore

# Findings

The concept of grief literacy was liked and understood

New definition:

Grief literacy means **knowing** about grief, **showing** support to grieving people, and **being** caring and compassionate to themselves and others

The term grief literacy is unclear

New term:



GriefAware



# Findings

Created scenarios that showed:

a range of losses such as the death of a close person or pet, life transitions, relationship break-ups, identity changes, and personal crises and in different contexts—school, community, family, work, peers, health professionals, etc.

what young people want—to be listened to, have their grief normalised and validated, and for people to check in with them over time.

what young people don't want—outdated ideas, clichés, and unsolicited advice.

They wanted findings shared via **infographics, videos, posters, and talks.**







## Video shorts

- *What is grief?*
- *Is grief common for young people?*
  - *When does grief end?*
- *How can I help a grieving friend?*
  - *Are there stages of grief?*

< **griefandyoungpeople** 🔔 ...

 **Grief and Young People Curtin**

<b>25</b> posts	<b>142</b> followers	<b>6</b> following
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Outreach page for a Curtin University study on supporting young people with grief.  
Engage with some resources at the link below.

[heylink.me/griefaware](https://heylink.me/griefaware)



# Grief and Young People

Helping Yourself or a Friend

## What do young people say about grief?

- You're not alone! Grief in young people is common.**  
It's something that you go through throughout life, a path you have to walk down.
- Grief is a response to a range of losses:**  
such as the death of a close person or pet, parents' divorce, job loss, life transitions, relationship break-ups, identity changes and world crises.  
You grieve so many different things. But you grieve it all differently.
- The experience of grief is unique to every person.**  
People grieve in many different ways. It varies from person to person.
- Grief has lots of different parts to it.**  
Grief has emotional, psychological and physical dimensions.
- Grief doesn't have a set pattern or timeline.**  
It's not something that happens and you get over it. You learn to surf the waves better. The grief is there, and you get better at dealing with it.
- Not all grief is recognised or validated.**  
There is so much unsolicited advice and it's tokenistic and it doesn't help.
- Grief can affect the whole family system.**  
There are multiple people grieving and it can be hard to support each other when going through grief.
- Grief can be irrational.**  
There's also this guilt that comes with, like, thinking I "should" have done this and that, it's quite illogical, it's quite irrational, but it's still there and it's hard to deal with on your own.
- It's okay to have boundaries about what you tell people.**  
If you're not ready to hang out, that's okay. You don't have to tell people your story. Tell them in their own time.
- Grief is normal but is also linked to mental health problems.**  
The mental health aspect isn't taken as seriously but it can be really tough.



## How to help a grieving friend:

- Listen**  
Acknowledge my thoughts and feelings. Listen to understand, not to respond or fix it.
- Normalise and validate**  
Make me feel heard, validated, understood.
- Respect choice**  
Provide the option to talk. Ask, "Do you wanna talk about it?" Say, "I'm not going to push you to talk but if you want to talk, I'm here."
- Check-in over time**  
It doesn't have to be one conversation. Reach out to let me know you're there.
- Look after yourself**  
When you're helping someone, it's okay to give yourself time and space and let yourself feel what you need to feel, too.



## What NOT to do:

- Avoid out-dated ideas**  
Avoid ideas like "stages of grief" or "getting over it".  
You go through the stages over and over again in different orders. I needed help to move forward, not to forget what happened.
- Avoid clichés and platitudes**  
Don't tell me it will get better in time. I'm not in that time and you're not helping me.
- Avoid unsolicited advice**  
I need support, not solutions or advice about what I "should" do.
- Avoid making it about you**  
Don't pretend you understand. Don't divert the conversation back to your experience.

Designed by Emily Rose Lockhart, 2024



Want to find out more?  
Head to [heylink.me/griefaware](https://heylink.me/griefaware) or scan the QR code



## SUPPORTING A GRIEVING YOUNG PERSON

A guide for teachers, parents, counsellors, chaplains, psychologists, youth workers, nurses, and doctors

### What young people (aged 14-24) want you to know about the evidence:

- Grief in young people is common**  
By the age of 10, up to 60% of children report being bereaved by the death of a person who was close to them<sup>(1)</sup>  
By the end of high school, 90% of adolescents have experienced the death of a family member or friend<sup>(2)</sup>



- Grief is a response to a range of losses**  
Young people report grieving non-death losses such as parents' divorce and relationship break-ups<sup>(3)</sup>

- Grief is unique to each person, and doesn't have a set pattern or timeline**  
Grief is a dynamic process, based on the characteristics of the grieving person and the circumstances of loss, involving ongoing adjustment to loss over time<sup>(4)</sup>



- Grief is normal but is also linked to mental health problems**  
Grieving young people are at an increased risk of anxiety, depression, substance use, self-harm and suicide attempts, poorer physical health, and reductions in educational attainment<sup>(5-7)</sup>

- Grieving young people don't get the support they need**  
Grief is typically overlooked when young people seek mental health support<sup>(8)</sup>  
Young people experience barriers to accessing support such as long waitlists and costs, and want adults around them to be better equipped to help them<sup>(9)</sup>



Sources: (1) Paul & Vaswani (2020) Palliative Care and Social Practice, 14. (2) Ena & Bond (2005) Death Studies, 29, 171-178. (3) Breen et al (2023) Journal of Affective Disorders, 335, 289-297. (4) Guidini & Legat (2023) Death Studies, 48, 738-752. (5) Weinstein et al (2023) Frontiers in Psychiatry, 12. (6) Pham et al (2018) American Journal of Psychiatry, 175, 887-896. (7) Hopyah et al (2022) The Lancet Public Health, 7, e683-e693. (8) Krentler & Kaplow (2020) Lancet Child and Adolescent Health, 4, 889-898.

(Designed by Tyesha Shelton, 2024)



Want to find out more?  
Head to [heylink.me/griefaware](https://heylink.me/griefaware) or scan the QR code



TO FIND OUT MORE:  
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## SUPPORTING A GRIEVING YOUNG PERSON

A guide for teachers, parents, counsellors, chaplains, psychologists, youth workers, nurses, and doctors

### Developed by young people aged 14-24 years

#### PLEASE DO...



- LISTEN**
  - Acknowledge my thoughts and feelings
  - Listen to understand, not to respond or fix it
- NORMALISE AND VALIDATE**
  - Make me feel heard, validated, and understood
- RESPECT AUTONOMY**
  - Provide the option to talk
  - Ask "do you wanna talk about it?"
  - Say "I'm not going to push you to talk but if you want to, I'm here"
- PROVIDE RESOURCES**
  - If you don't have the capacity to help someone who's grieving, connect them to a person or a programme that can help them
- CHECK-IN OVER TIME**
  - It doesn't have to be one conversation
  - Reach out to let me know you're there



#### PLEASE DON'T...



- USE OUTDATED IDEAS LIKE 'STAGES OF GRIEF' OR 'GETTING OVER IT'**
  - You go through different stages over and over again, and in different orders
  - I need help to move forward, not to forget what happened
- USE CLICHES AND PLATITUDES**
  - Don't tell me it will get better in time
  - I'm not in that time, and you're not helping me
- TREAT ALL YOUNG PEOPLE THE SAME**
  - Don't pigeon-hole all young people who are grieving, into a box
  - Everyone can be very different
- PROVIDE UNSOLICITED ADVICE**
  - I need support, not solutions or advice about what I "should" do
- MAKE IT ABOUT YOU**
  - Don't pretend you understand
  - Don't divert the conversation back to your experience

(Designed by Tyesha Shelton, 2024)



Want to find out more?  
Head to [heylink.me/griefaware](https://heylink.me/griefaware) or scan the QR code



TO FIND OUT MORE:  
Head to [heylink.me/griefaware](https://heylink.me/griefaware) OR scan the QR code



Kate is in her final year of high school when a classmate dies pretty unexpectedly. The school takes the initiative to respond in a way that recognises the young person who has died and respects the different ways each student grieves the loss. The staff and students gather in the gym. The principal acknowledges the sadness in the room, and that nothing is going to take away the sadness that day, and makes it clear that there are numerous people available to support the students.



Image by <https://unsplash.com/@hossebmohi>

Students later find out that exam dates were pushed back and feel relieved that their emotional and academic needs are supported. Students who were close to the classmate also are given grace if they needed days away from school and/or needed to step out of the classroom.



14-year-old Andrew is feeling lost after his childhood dog's death. After school, Andrew tells a few mates about what happened. They share their own stories of the loss of their own pets. Andrew was comforted to know that he wasn't alone in his feelings, that it is ok to talk about his dog, and that he would be ok.



Designed by Aysa Bahar Arjmand 2024  
Image by <https://pexels.com/@cottonbro studio>

Jessie is at a café with friends when a memory of her loss comes into her mind. One of her friends, Anna, notices Jessie's face change.

Anna understands the importance of allowing people to show emotion rather than hiding it. She moves closer to Jessie, to allow space for the expression and to listen without telling her to quickly hide her feelings or toughen up.

Anna asks, "would you like to talk about what you're thinking about?" Jessie appreciates the question isn't a demand to explain herself and says, "not now, but when we get back to my place, I'd love to talk about it with you."



IMAGE BY [HTTPS://UNSPLASH.COM/@DANNYKANG](https://unsplash.com/@dannykang)



Invited address at the “Let’s Talk About Grief” conference,  
Aotearoa/New Zealand (May 2024)

Keynote address at the “Grief Literacy Symposium: Exploring Grief,  
Loss, and Resiliency in Our Community and on Campus,” Canada  
(Sept 2024)

**Co-hosted the “Innovations for Grief in Youth” event (Nov 2024)**

**Lionheart Camp for Kids AGM (Dec 2024)**

**School Psychologists Association of WA (May 2025)**

**“Grieving While Growing Up” symposium as part of the 33<sup>rd</sup>  
Meeting of the International Work Group on Death Dying and  
Bereavement (June 2025)**

**Invited webinar for the Grief Centre of New Zealand,  
Aotearoa/New Zealand (Aug 2025)**

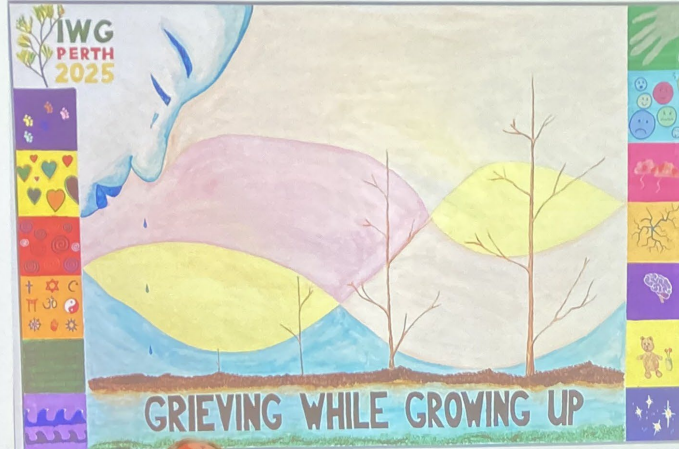
Invited address at the 45<sup>th</sup> National Conference of the Australian  
Association for Cognitive and Behaviour Therapy, Perth (Oct 2025)





# "Grieving While Growing Up" Symposium

Pre-meeting conference of the 33<sup>rd</sup> Meeting of the International Work Group on Death, Dying and Bereavement



Curtin University

City of Fremantle

LION HEART

healthway

foodfolk AUSTRALIA

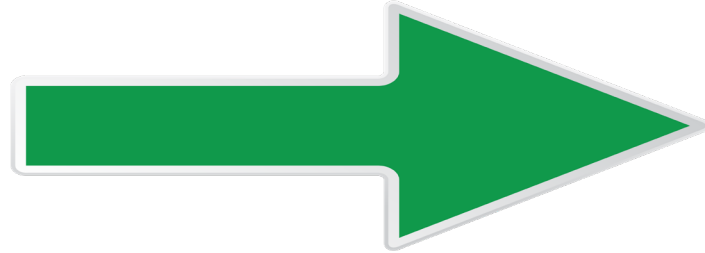
BUSINESS  
EVENTS  
PERTH



# Additional resources

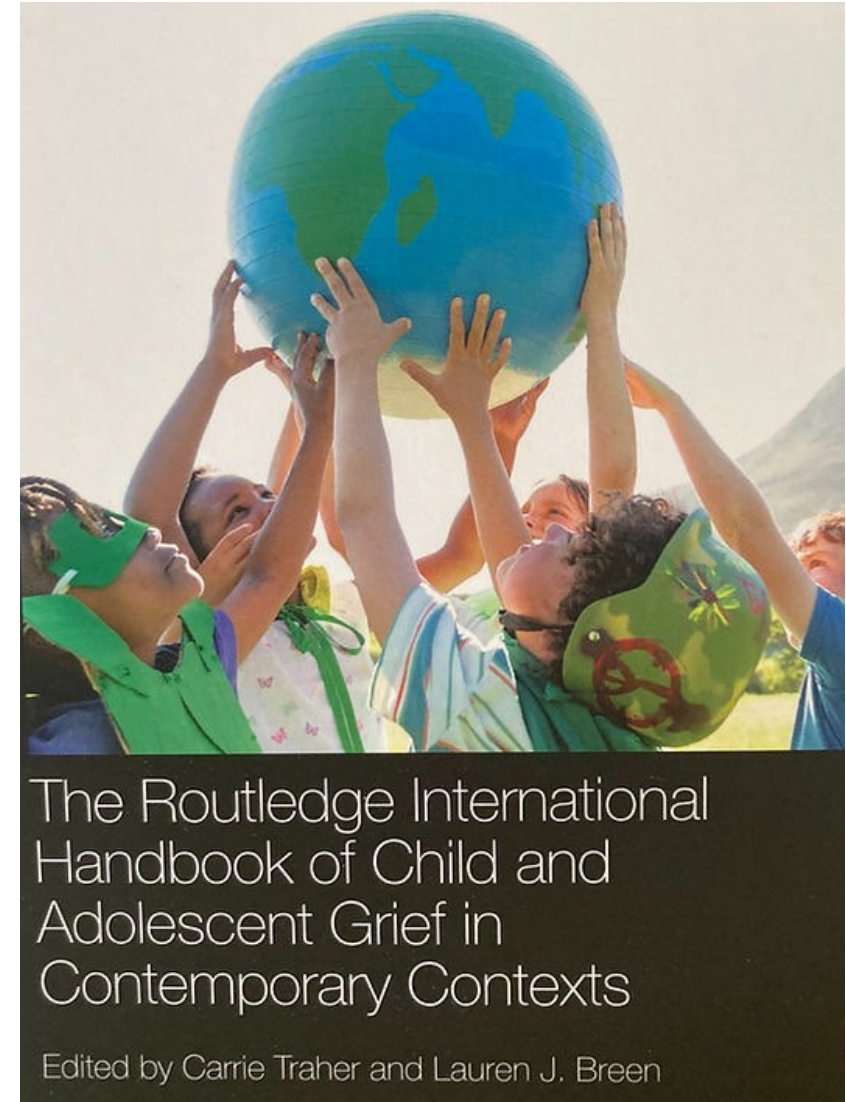
My website [www.drlaurenbreen.com](http://www.drlaurenbreen.com) – lots of information, including videos and downloadable infographics

My book

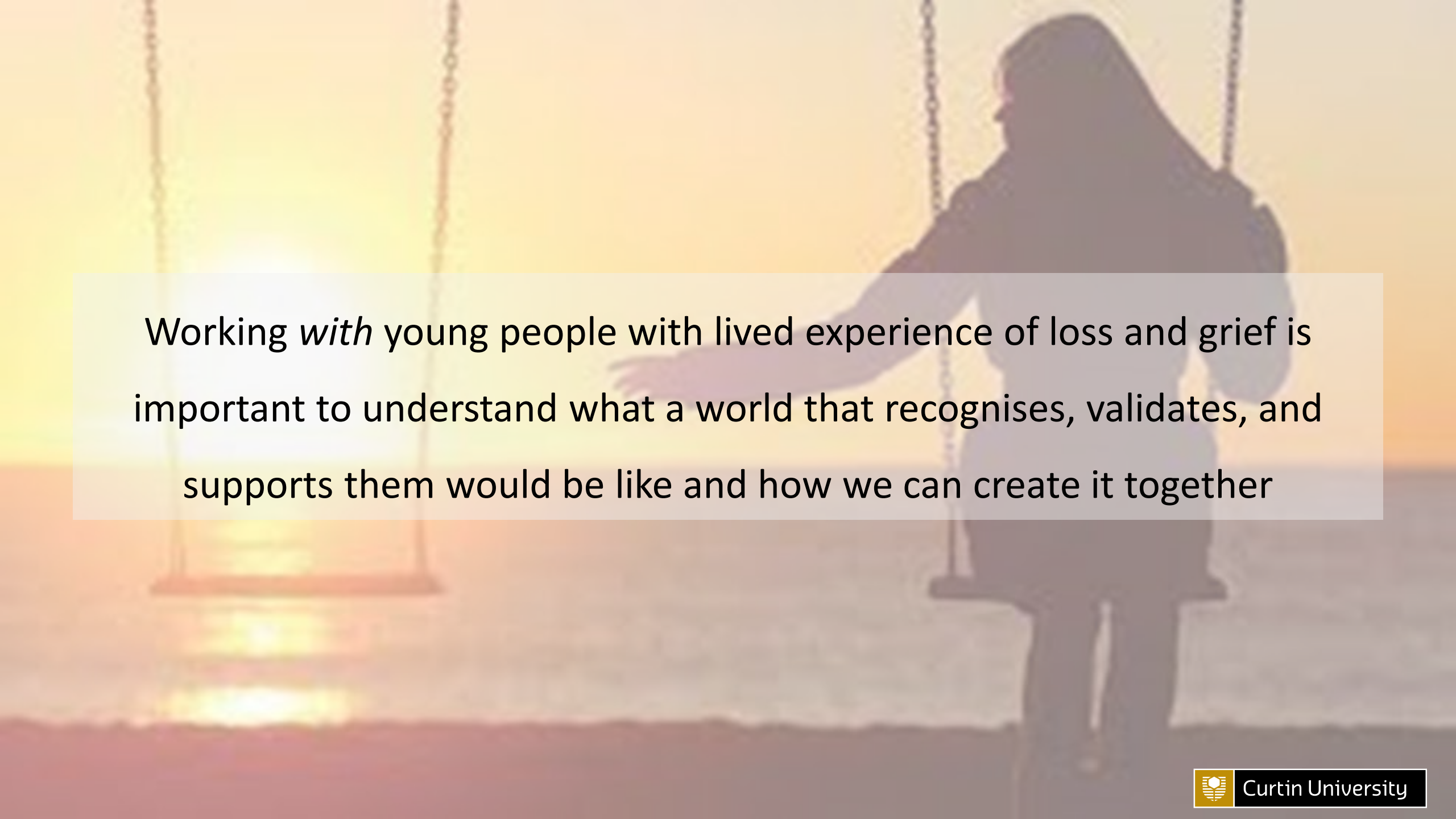


Supporting Adolescents in Loss (SAIL)  
<https://www.sailgrief.org/> – an effective CBT program for grieving kids aged 13-18.

Supporting Kids in Loss (SKIL) – developing a program for grieving kids aged 6-12.





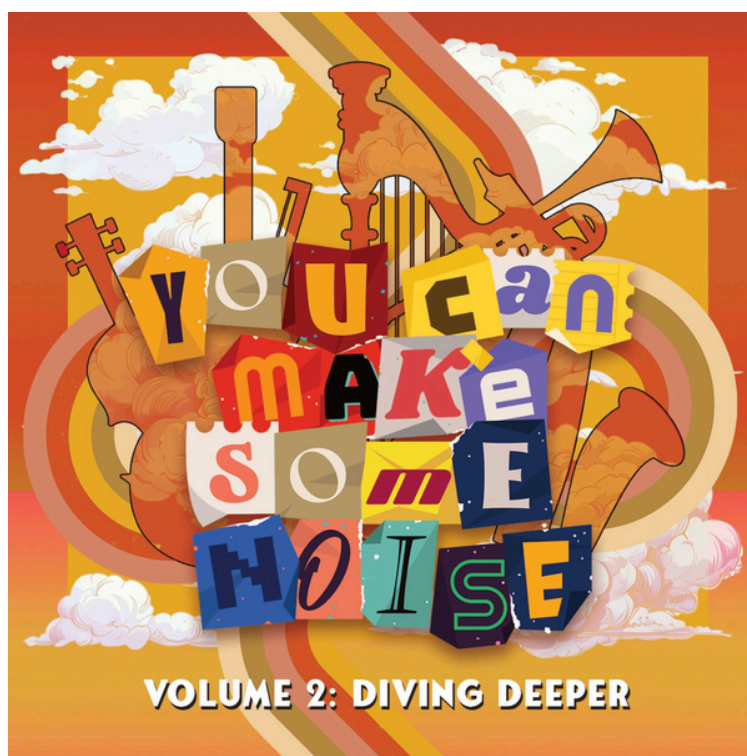
A person is sitting on a swing, silhouetted against a warm, golden sunset sky. The person's hair is long and flowing. The swing is in motion, and the background is a soft, hazy landscape. The overall mood is contemplative and serene.

Working *with* young people with lived experience of loss and grief is important to understand what a world that recognises, validates, and supports them would be like and how we can create it together



# Ainslie's resources

- You can make some noise (Ainslie's band)
- Precious Wings - legacy boxes



To listen to You Can Make Some Noise on Apple Music  
or Google them

Good  
grief,  
this  
hurts!



# legacy boxes

“A tangible way to leave *love, connection* and *memories* behind”



**Legacy is a powerful part of end-of-life care**, especially for adolescents and young adults.

It offers comfort, purpose, and a sense of meaning beyond death – supporting dignity, agency, and emotional well-being during a profoundly difficult time.

In **December 2024, Precious Wings**, in collaboration with the **Queensland Youth Cancer Service (QYCS)** and the **QYCS Youth Advisory Group (YAG)** at Queensland Children's Hospital, launched a heartfelt initiative – **The Legacy Memory Box** for Adolescents and Young Adults with a terminal diagnosis.

These boxes are designed to:

- ☉ Help create lasting memories
- ☉ Support difficult conversations
- ☉ Honour the young person's individual wishes and legacy

What's Inside the Box:

- ☉ **Video Book and USB Stick**  
Record and store messages for loved ones
- ☉ **Finger Mould and Handprint Kits**  
Create keepsakes or jewellery
- ☉ **Writing Paper with Envelopes and a Journal**  
Writing letters and preserving precious handwriting
- ☉ **Funeral and Advance Care Planning Tools**  
To explore hopes and wishes
- ☉ **Identical Teddies**  
With a pocket for a voice or heartbeat recording
- ☉ **Items for Remembrance and Reflection**  
Candle, Seeds, Lock of Hair Bag, Photo Frame
- ☉ **Personalisation Options**  
Photos, special items and more

These tools provide young people with the opportunity to express *who they are*, what they value, and how they wish to be remembered – *on their own terms*.

For more information and to view our video, please click on the below QR Codes.

What is a  
Legacy Box?



Introducing  
a Legacy Box



Precious Wings  
Website



## Our Goal

To expand the Legacy Box program across Australia so every young person facing end of life has equitable access. This includes:

- ☉ Availability for all terminal diagnoses
- ☉ Training health professionals in legacy-making
- ☉ Ensuring cultural inclusivity for First Nations peoples and other communities



# Introducing the legacy box to young people: A communication guide



## Key Principles

- 🕒 **Invite, don't impose** – the box is an option, not a requirement
- 🕒 **Pace matters** – allow silence, give time, and offer to return later
- 🕒 **Acknowledge emotions** – validate both grief and hope for meaning-making
- 🕒 **Timeliness** – Introduce early enough to allow for reflection and creativity

## Communication Prompts

### 🕒 **Introducing the Legacy Box**

"We have something called a Legacy Box. It's a way for you to record memories, messages, or things that are important to you"

"Some young people use it to leave notes, videos, or keepsakes for family and friends"

"You can choose what feels right for you there's no 'right way' to use it"

### 🕒 **Checking readiness**

"Would you like to see what's inside, or would you prefer me to explain first?"

"Is this something you'd like to think about now, or later?"

### 🕒 **Supporting meaning-making**

"Sometimes people say it helps them feel a sense of control"

"What kinds of things feel important for you to leave or share?"

"You mentioned wanting your sister to remember you. Would you like to make something special for her?"

"Some people write letters, record messages, or add photos – would you like me to show you some examples?"

## Tips & Tricks

- 🕒 Start with curiosity: *"Have you ever thought about..."*
- 🕒 Encourage **choice and autonomy** – let the young person lead
- 🕒 Give the young person **permission not to engage** – that can be empowering
- 🕒 Acknowledge emotions: *"This can feel hard, but also really special"*
- 🕒 Keep sessions short and manageable – grief and fatigue limit concentration
- 🕒 Include **siblings, parents, or peers** where appropriate
- 🕒 Offer **follow-up support** – "Would you like me to check in with you about this later?"

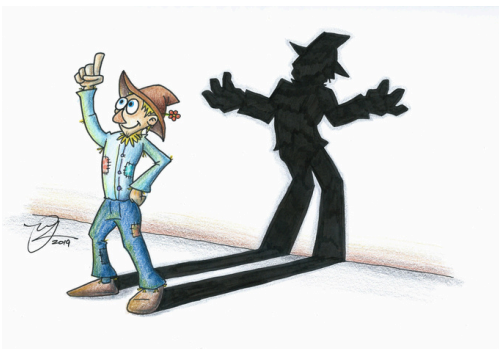
## Key Learnings

- 🕒 Legacy work supports dignity, identity, and connection
- 🕒 Families often express deep gratitude for the opportunity afterwards
- 🕒 Health professionals play a vital role in **opening the door gently** – individuals and families rarely regret being offered, but they may regret not being given the chance
- 🕒 The Legacy Box is not about dying but about **connection, meaning, and ongoing bonds**
- 🕒 When introduced well, the Legacy Box can reduce distress, enhance family connection, and support healthy grieving

**Remember** – your role is to invite and support, not to direct. The Legacy Box is most powerful when it reflects the young person's unique voice and choices.

# Additional resources

- Learning through loss resources
- Caresearch - Australian children's books on death and dying
- General links and resources provided by the GGTH 2025 panel



**Listening to and understanding lived expertise.**  
**Some people without brains do an awful lot of talking ...**  
(The Wizard of Oz)



**Exploring our personal relationship with grief**  
**Now I know I've got a heart, 'cause it's breaking...**  
(The Wizard of Oz)



**Actively supporting grieving children and young people**  
**The true courage is in facing danger when you are afraid...**  
(The Wizard of Oz)

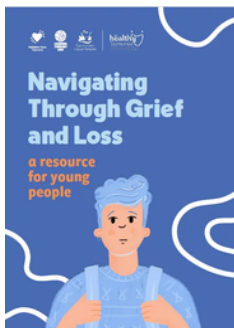
Artist - Jason Lynch father of Oscar  
Re-imagined images from The Wizard of Oz

# Learning Through Loss

<https://learningthroughloss.org.au/>

Learning Through Loss is a nationally recognised program by Palliative Care Tasmania that builds grief literacy for educators, health professionals, and community workers. It equips them with the skills and confidence to support children and young people through grief and loss, drawing on the voices and lived experiences of young people.

Grounded in public health principles, the program addresses diverse forms of grief—bereavement, family breakdown, illness, friendship loss, and major life changes. It provides evidence-informed training, practical tools, and accessible resources to foster compassionate, grief-literate schools and communities.



[Navigating Through Grief and Loss – a resource for adolescents](#)



[Grief literacy poster for adolescents](#)



[What is Grief?](#)



[This is Grief- a gentle guide for individuals and families](#)



[Your Circle of Support-Worksheet](#)





The books in this list have all either won award(s) or been nominated or shortlisted for award(s). You can use them as starting point when talking to children about death and dying, how to cope with grief, and the importance of remembering loved ones who have died.

## Babies and Toddlers (0 - 4 years)

### **A Leaf Called Greaf (2024). Kelly Canby**

A lonely bear forms a strong connection with a special leaf named Greaf. As Greaf changes through the seasons and eventually drifts away, Bear feels the pain of loss but ultimately finds hope and comfort in the cherished memories that they shared.



### **Grace and Mr Milligan (2024). Caz Goodwin**

Grace, a young girl, shares happy moments with her neighbour Mr Milligan and his goat Charlie until Charlie passes away from old age, causing Mr Milligan to retreat in sorrow. Concerned, Grace plans a picnic where they share memories, helping Mr Milligan to heal and find joy again through the power of love and friendship.

### **Harry & Hopper (2024). Margaret Wild**

One day, when Harry comes home from school, his beloved dog Hopper is not there to greet him. This story explores the deep bond and the sadness Harry feels after losing Hopper, and helps children make sense of grief and understand the enduring power of love and memories.



### **Tough Boris (2019). Mem Fox**

Tough guys need to cry, even tough guy pirates! Tough Boris tells of the importance of acknowledging emotions, acceptance of death and experiencing grief. All of these big emotions are experienced by Boris when his beloved parrot dies, while a boy who stows away on Boris' pirate ship helps Boris through this tough period.

## Little kids (5 - 7 years)

### **Jenny Angel (2002). Margaret Wild and Anne Spudvilas**

Jenny sees herself as her younger brother's guardian angel, determined to keep him safe from his life-threatening illness. Through her nightly vigil and steadfast hope, Jenny comes to accept the reality of loss and discovers the importance of love and memory in the face of grief.

### **Old Pig (2017). Margaret Wild and Ron Brooks**

An elderly pig and her granddaughter share a peaceful, tender farewell as the older pig prepares for her passing. In their final moments together, they cherish simple joys, gently reflecting on love, loss, and the beauty of life's fleeting moments.



**The Important Things (2025). Peter Carnavas**

The story follows young Christopher and his mother as they try to move on after his father has disappeared from their lives. When they begin giving away Christopher's father's belongings, the items mysteriously reappear, revealing Christopher's silently holding onto his memories, while his mother learns to honour his need to remember.

**The Tiny Star (2021). Mem Fox**

A tiny star falls to the earth and becomes a baby, living a loving fulfilling life as years go by, under the loving care of the community. As the star begins to shrink over time and then disappears completely one day, the community feels the loss but later realises that the star has simply returned to its home in the heavens where it continues watching over and loving them.



**The Very Best of Friends (2004). Margaret Wild**

Jessie and her husband James live happily on a farm with their beloved cat until James suddenly dies. Overcome with grief, Jessie distances herself from the cat—but as time passes, their quiet companionship helps her heal and rediscover comfort in love and friendship.

**Big Kids (8 – 12 years)**

**Bailey Finch Takes a Stand (2021). Ingrid Laguna**

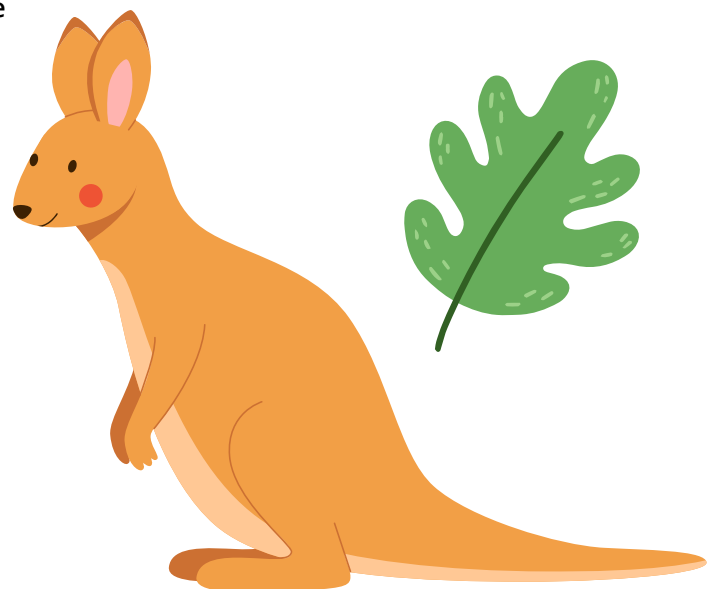
Bailey is mourning her mother's passing and finds comfort in spending time by the creek with her dog, Sheba. When Sheba becomes seriously ill from swallowing glass in the polluted water, Bailey forms an unexpected friendship with Israel, a quiet boy knowledgeable about endangered species, as they clean up the creek together and learn about courage and environmental responsibility along the way.

**Leave Taking (2018). Lorraine Marwood**

Toby and his parents prepare to leave their family farm following the death of his younger sister, Leah. Over the course of a week, Toby revisits meaningful places around the property, guided by memories of Leah and his faithful dog, Trigger, learning to say goodbye and find healing through their shared history.

**Lucy's Bay (2003). Gary Crew and Gregory Rogers**

A teenage boy returns to his grandfather's beach house after many years, confronting the painful memory of his younger sister Lucy's drowning, an event which he blames himself for. As he revisits the bay where the tragedy occurred, he confronts his guilt and sorrow, ultimately finding a path toward healing and reconciliation.





**Pie in the Sky (2020). Remy Lai**

Jingwen relocates from China to Australia with his mother and younger brother, Yanghao, following his father's sudden death. Struggling with loneliness and a language barrier, Jingwen finds comfort in baking cakes inspired by his father's dream of owning a bakery, all while keeping this secret from his mother.

**The Elephant (2021). Peter Carnavas**

A girl named Olive imagines her father's depression following the death of Olive's mother as an elephant that follows him everywhere. With help from her cheery grandfather and her best friend, Arthur, Olive sets out to chase the elephant away.



**The Naming of Tishkin Silk (2013). Glenda Millard**

Griffin Silk is an uncommon boy from an uncommon family, and live with his father, grandmother, and five sisters in a warm, loving home. Troubled by the absence of his mother and baby sister, Griffin's world shifts when he befriends Layla, a spirited classmate who helps him confront his feelings and understand the changes in his family.



## Teenagers (13 – 16 years)

**Bridge of Clay (2018). Marc Zusak**

This story explores the impact of parental death on family bonds and the importance of brotherhood in maintaining a sense of normality in relation to the real, adult world, especially when faced with a sense of abandonment and heartbreak.

**How It Feels to Float (2023). Helena Fox**

16-year-old Biz struggles with a profound sense of detachment and isolation following her father's passing. When she starts seeing her father's spirit, it challenges her sense of reality and leads her to confront her inner turmoil, where she begins to discover the importance of connection, self-acceptance, and healing.

**Painted love letters (2015). Catherine Bateson**

A heartfelt novel about Chrissie, a teenage girl coping with her father's terminal illness and the emotional challenges it creates within her family. Through art, poetry, and reflection, Chrissie begins to navigate grief, love, and growing up.



**The Grief Book (2010). Elizabeth Vercoe with Kerry Abramowski**

A compassionate resource to help young individuals navigate the complex emotions associated with grief. Featuring 52 practical strategies, the book offers coping mechanisms, personal stories, and insights to support readers in comprehending and coping with their grief, whether from the loss of a loved one, family changes, or other significant life events.

**The Messenger Bird (2014). Rosanne Hawke**

Tamar is mourning the loss of her older brother, and the emotional distance between her and her father grows as they both struggle with their grief. Her path toward healing begins when she discovers an old piece of music and reconnects with her piano, which leads her to meet Nathaniel, a gifted violinist who helps her find a path forward.



**The Protected (2018). Claire Zorn**

Hannah struggles to rebuild her life following the sudden death of her older sister in a car accident. As she copes with grief, strained family relationships, and the aftermath of past bullying, Hannah finds unexpected support from a new student named Josh, helping her confront her pain and heal.



**The Simple Gift (2019). Steven Herrick**

Billy runs away from his difficult home life and finds refuge in an abandoned train carriage in the quiet Australian town of Bendarlat. There, he forms unexpected friendships with Old Bill, a reclusive homeless man, and Caitlin, a wealthy girl seeking meaning, where together they discover the transformative power of kindness and human connection.

**This Is Not a Sad Book (But It's OK to Feel Sad) (2024). Liz Vercoe**

A practical, compassionate guide filled with stories and ideas to support children through their grief and loss. It reassures us that even in our darkest moments, there is a path forward.



Visit [caresearch.com.au/Dying2Learn](https://caresearch.com.au/Dying2Learn) for more information and resources.

CareSearch is funded by the Australian Government Department of Health, Disability and Ageing.  
October 2025

# General links & resources

provided by the GGTH 2025 panel

## **Professor Lauren Breen**

- Instagram page: @griefandyoungpeople
- Supporting Adolescents in Loss website: <https://www.sailgrief.org/>
- Articles about young people's desires for grief support

[A world that recognizes, validates, and supports young people's grief: A co-designed study](#)

[A co-designed systematic review and meta-analysis of the efficacy of grief interventions for anxiety and depression in young people](#)

- Books on children and adolescent grief in contemporary contexts available [here](#)

## **Meg Chin**

- Re-Imagining Childhood Grief: Children as Active Agents in a Transactional Process  
<https://journals.sagepub.com/doi/10.1177/00302228241310264>

- NACG Rights of the Grieving Student  
[https://nacg.org/resources\\_directory/griefftalk-schools-rights-of-a-student-who-is-grieving/?srsId=AfmBOogW3MTL6-vFuWh8UMD5xcINeVqIPwUsrrOSALT7nMv2xy\\_yCh2g](https://nacg.org/resources_directory/griefftalk-schools-rights-of-a-student-who-is-grieving/?srsId=AfmBOogW3MTL6-vFuWh8UMD5xcINeVqIPwUsrrOSALT7nMv2xy_yCh2g)

- United Nations Convention on the Rights of the Child  
<https://www.unicef.org/media/56661/file>

- Becoming grief informed – a call to action  
[https://www.dougy.org/assets/uploads/Becoming-Grief-Informed\\_A-Call-to-Action.pdf](https://www.dougy.org/assets/uploads/Becoming-Grief-Informed_A-Call-to-Action.pdf)

## **Shelly Skinner**

- [Puddle Jumping animation](#) - Child Bereavement UK
- StandBy - [Home](#)

# *Thank you*

Thank you for taking the time to read this booklet. We hope it has provided comfort, guidance, and practical support during a difficult time. Grief and loss are deeply personal experiences, and there is no right or wrong way to navigate them. Please remember to be gentle with yourself and allow space for reflection and healing.

Self-care matters. Whether it's resting, connecting with loved ones, or spending time in nature, small acts of care can make a big difference. We again encourage you to explore the GGTH Reflection Guide—it offers gentle prompts to help you explore feelings and find moments for peace.

Head to <http://www.quocca.com.au> to view previous years of GGTH recordings and access valuable resources.



[www.quocca.com.au](http://www.quocca.com.au)



[quoccaclined@health.qld.gov.au](mailto:quoccaclined@health.qld.gov.au)