



# TAMARIKI/RANGATAHI GRIEF IS EVERYONE'S BUSINESS



Dr Amanda Evans (she/her)  
Paediatrician and Palliative Care Specialist



vevo

# My hope:

- Tamariki/Rangatahi grief is everyone's business
- Tamariki/rangatahi grief will become visible in all aspects of our care
- I will share my top tips about providing bereavement care
- I will share resources with you to use when you need them

# It's common

- GUINZ study 35% 8 year olds experience childhood grief – 1% lost parents
- Violent deaths over 5 years – 104 lost parents, 110 lost siblings
- SCT deaths over 5 years – 28 siblings from 16 families

## **INTERNATIONAL DATA:**

- UK: 78% 11y – 16yr have someone close to them die.
- In 2015, 23,600 parents died leaving behind 41,000 children
- US: 1.5mil children are living with a single parent due to parental death.
- Canada: 1 in 14 children experience death of a parent or a sibling.

# Global, regional, and national minimum estimates of children affected by COVID-19-associated orphanhood and caregiver death, by age and family circumstance up to Oct 31, 2021: an updated modelling study

H Juliette T Unwin\*, Susan Hillis\*, Lucie Cluver, Seth Flaxman, Philip S Goldman, Alexander Butchart, Gretchen Bachman, Laura Rawlings, Christl A Donnelly, Oliver Ratmann, Phil Green, Charles A Nelson, Alexandra Blenkinsop, Samir Bhatt, Chris Desmond, Andrés Villaveces†, Lorraine Sherr†

Lancet Child Adolesc Health 2022

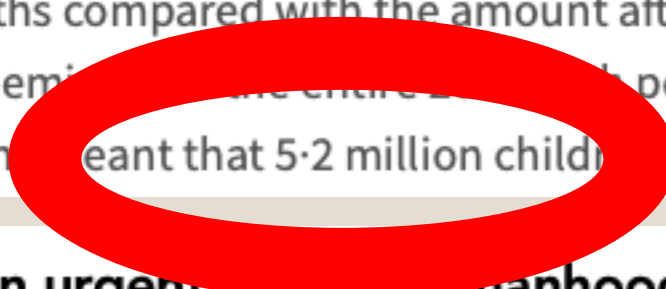
Published Online

February 24, 2022

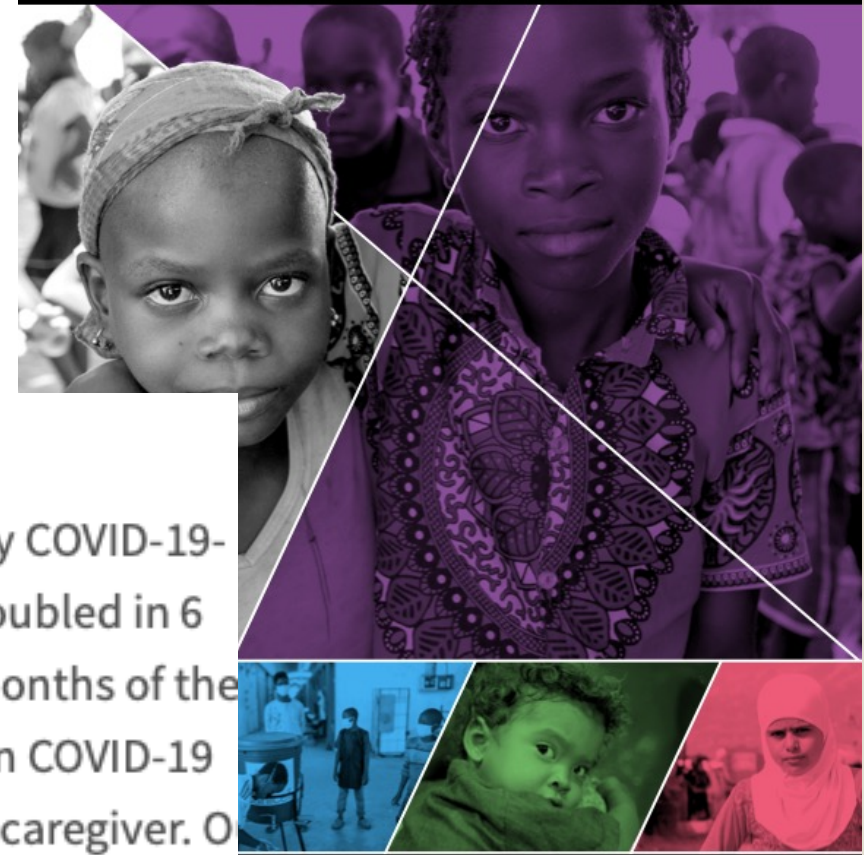
[https://doi.org/10.1016/S2352-4642\(22\)00005-0](https://doi.org/10.1016/S2352-4642(22)00005-0)

## Interpretation

Our findings show that numbers of children affected by COVID-19-associated orphanhood and caregiver death almost doubled in 6 months compared with the amount after the first 14 months of the pandemic. In the entire 18-month period, 5·0 million COVID-19 deaths meant that 5·2 million children lost a parent or caregiver. O



## Children: The Hidden Pandemic 2021



A joint report of COVID-19 associated orphanhood and a strategy for action

**COVID-19 has created an urgent global orphanhood and caregiver crisis, affecting children in almost every nation.** This wide-scale tragedy strips children of the mothers, fathers, grandparents and others who care for them and will require radically scaled-up national, regional, and community responses for at least two decades—especially in those nations where children’s lives have been most impacted.

LD BANK  
LAW GROUP

World Health  
Organization

UNIVERSITY OF CAPE TOWN  
UNIVERSITY OF CAPE TOWN

# It is an Adverse Childhood Event

- **Child Harm:**

- physical, emotional abuse
- physical, emotional neglect
- sexual abuse

- **Household Dysfunction**

- incarceration of family member
- household substance abuse
- household mental illness
- **loss of a parent**
- household partner violence

# Why – non-pathological

Loneliness

Invisible

Low self esteem

Helplessness

Stress

Separation

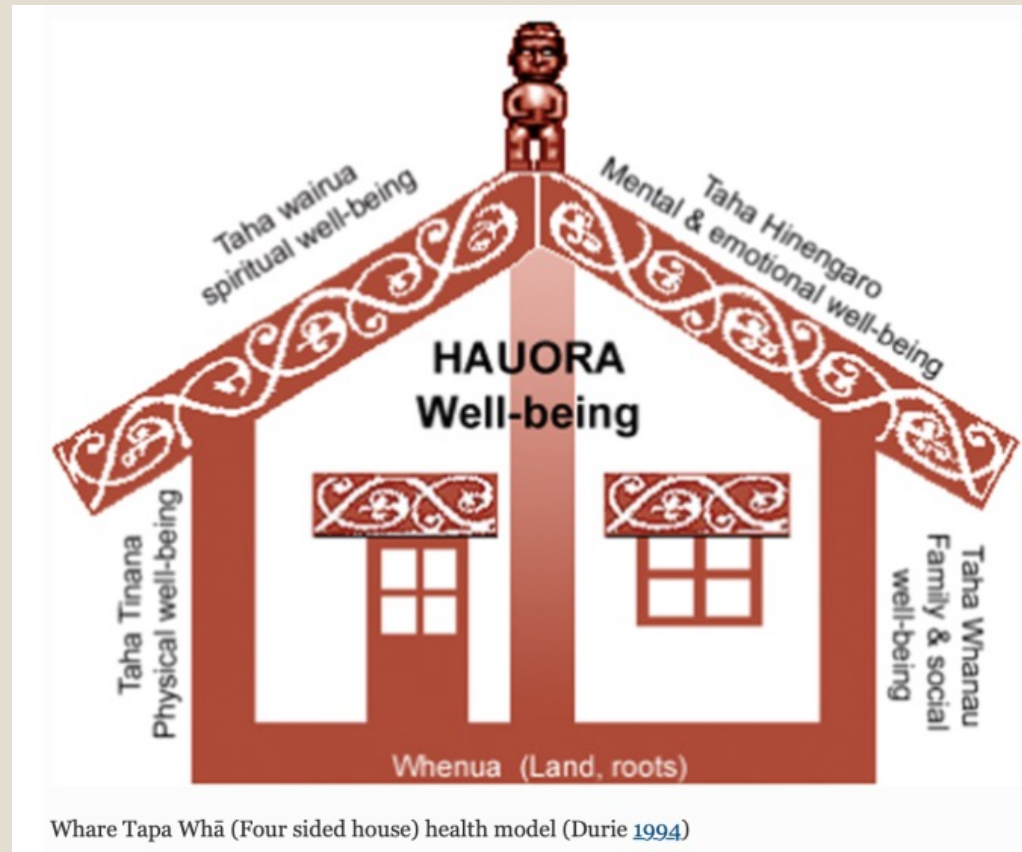
Fear

Guilt

Sadness



# Why - pathological





# Physical – During childhood

- Asthma 6.7% vs 13.1%
- Overweight/Obese 26.5% vs 38.6%
- Special health needs 14.6% vs 31.6%
- ADHD 4.8% vs 14.6%
- Developmental/behaviour/social delay 22.5% vs 37.5%
- Serious illness 10%
- Decreased age of menarche

Bethall  
Moffit et al 1992  
Worden 1996

# Physical - During adulthood

- More at risk of cancer
- Cardiovascular disease
- Type 2 Diabetes
- Allergies
- Accelerates biological aging
- Even facial aging
- Decreased life expectancy

Rasmussen et al 2020

Moffit et al 2014

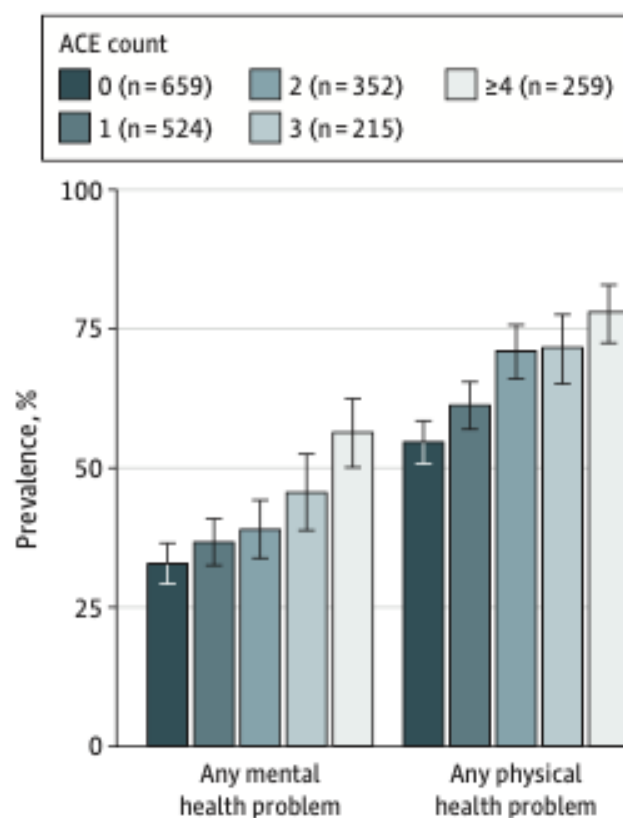
Shalev et al 2014

# Population vs Individual Prediction of Poor Health From Results of Adverse Childhood Experiences Screening

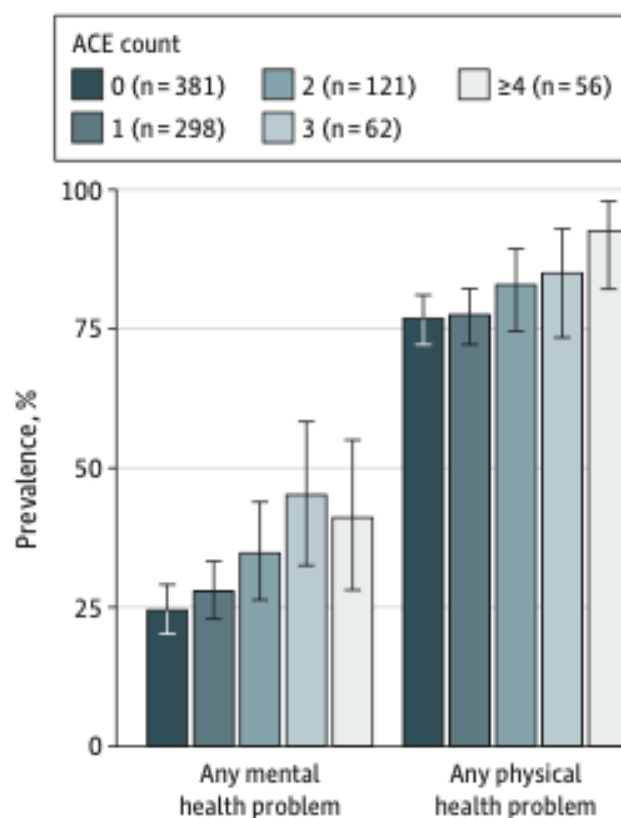
Jessie R. Baldwin, PhD; Avshalom Caspi, PhD; Alan J. Meehan, PhD; Antoinette Helen L. Fisher, PhD; HonaLee Harrington, BA; Timothy Matthews, PhD; Richie Poulton, PhD; Sandhya Ramrakha, PhD; Terrie E. Moffitt, PhD; An

*JAMA Pediatr.* 2021;175(4):385-393. doi:10.1001/jamapediatrics.2020.5602  
Published online January 25, 2021.

**A** E-Risk cohort, prospective measure



**B** Dunedin cohort, prospective measure

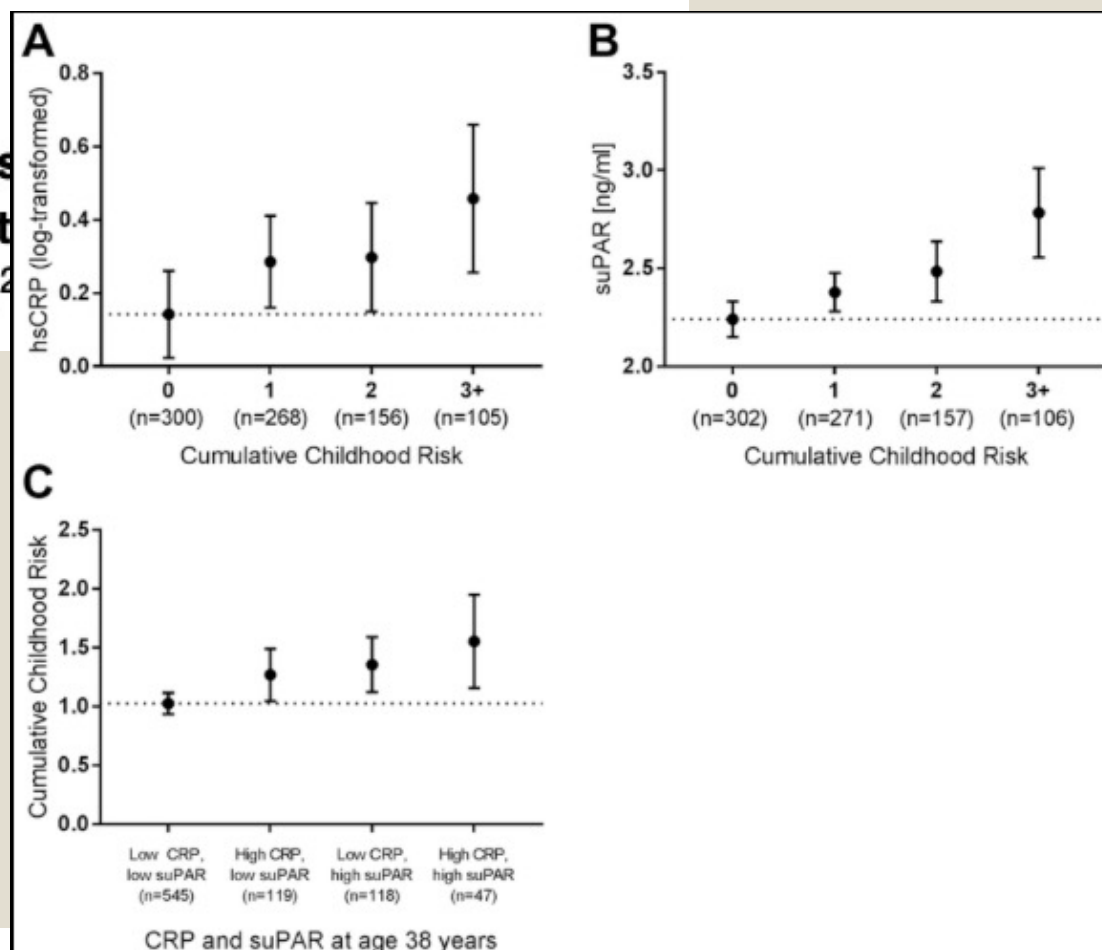


Published in final edited form as:

*J Child Psychol Psychiatry*. 2019 February ; 60(2): 199–208. doi:10.1111/jcpp.12928.

## Cumulative childhood risk is associated with a new measure of chronic inflammation in adulthood

Line Jee Hartmann Rasmussen<sup>1</sup>, Terrie E. Moffitt<sup>2,3,4,5</sup>, Jesper Belsky<sup>6,7</sup>, Andrea Danese<sup>5,8,9</sup>, Honalee Harrington<sup>2</sup>, Renata Karen Sugden<sup>2</sup>, Benjamin Williams<sup>2</sup>, and Avshalom Caspi<sup>2</sup>



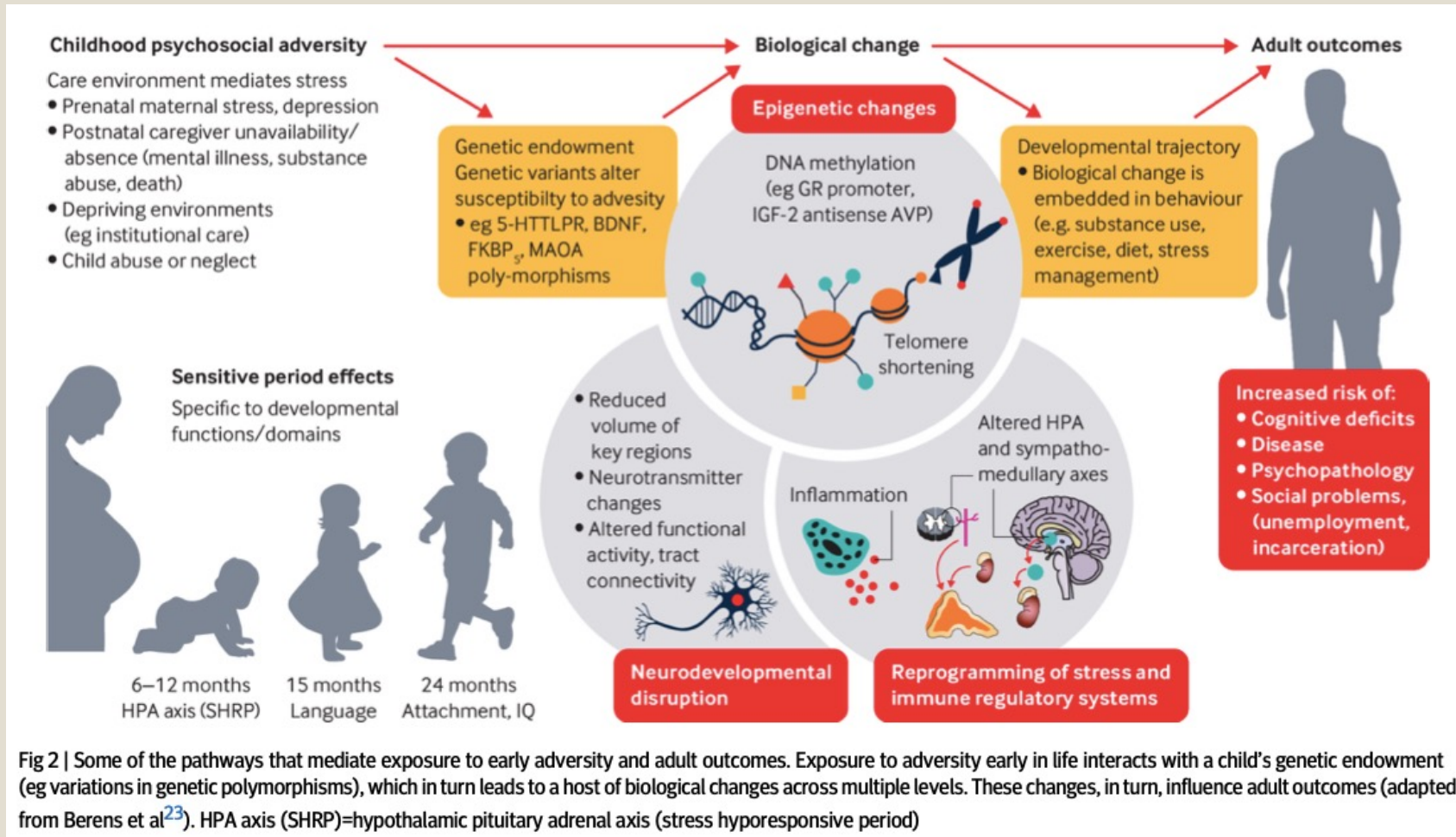
# Parental death in childhood and pathways to increased mortality across the life course in Stockholm, Sweden: A cohort study

**Ayako Hiyoshi** <sup>1,2,3,4\*</sup>, **Lisa Berg** <sup>2,5</sup>, **Alessandra Grotta**<sup>2,5</sup>, **Ylva Almquist**<sup>2</sup>,  
**Mikael Rostila**<sup>2,5</sup>

**1** Clinical Epidemiology and Biostatistics, School of Medical Sciences, Örebro University, Örebro, Sweden, **2** Department of Public Health Sciences, Stockholm University, Stockholm, Sweden, **3** Department of Epidemiology and Public Health, University College London, London, United Kingdom, **4** Public Health, Department of Social Medicine, Osaka University Graduate School of Medicine, Osaka, Japan, **5** Centre for Health Equity Studies, Stockholm University/Karolinska Institutet, Stockholm, Sweden

\* [ayako.hiyoshi@oru.se](mailto:ayako.hiyoshi@oru.se)

# Biography becomes biology



Nelson et al 2020

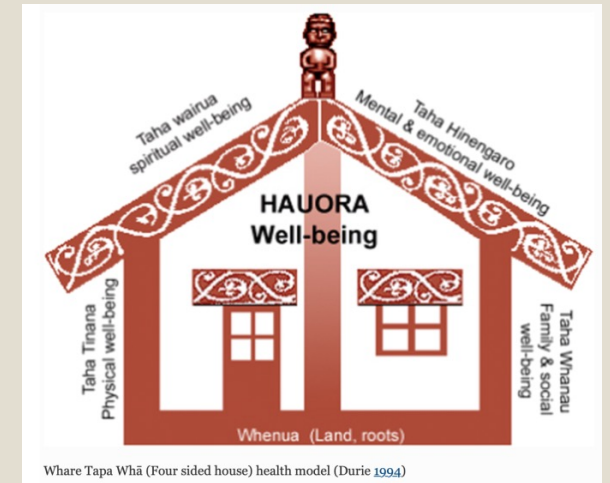
Fig 2 | Some of the pathways that mediate exposure to early adversity and adult outcomes. Exposure to adversity early in life interacts with a child's genetic endowment (eg variations in genetic polymorphisms), which in turn leads to a host of biological changes across multiple levels. These changes, in turn, influence adult outcomes (adapted from Berens et al<sup>23</sup>). HPA axis (SHRP)=hypothalamic pituitary adrenal axis (stress hypo-responsive period)

# Emotional

- Increased risk of anxiety
- Increased risk of depression

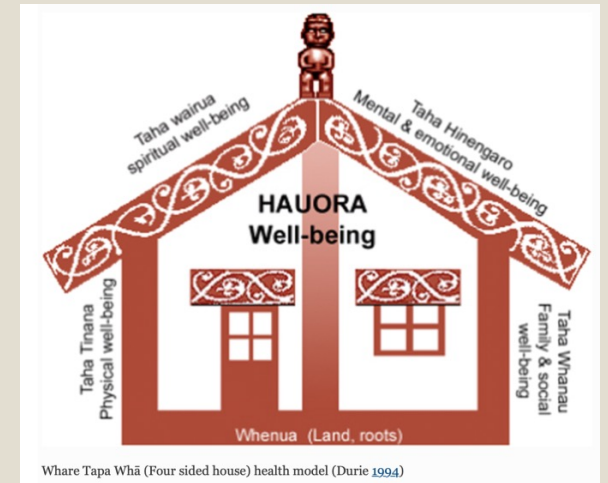
- Increased PTSD – of all the ACE it is parental death and maternal distress that increases this. 67% vs 25% in normal population.
- Those who present to hospital with psychosis – 3 x more likely to be bereaved.

Harrison and Harrington 2001  
Worden et al 1996



# Learning

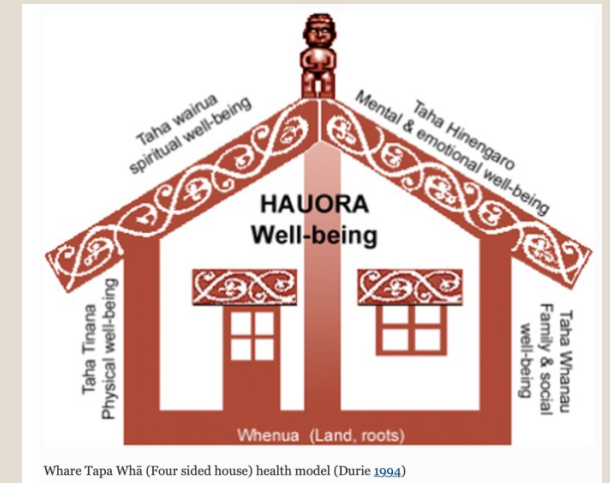
- Lower rates of school engagement
- Concentration
- Cognitive deficits
- Decreased general intelligence
- Decreased executive function
- Decreased processing speed
- Memory
- Perceptual reasoning
- Verbal comprehension





# Behaviour

- Increased likelihood smoking by 15yr
- Increased likelihood drinking by 18yr
- Increased likelihood sexual activity by 15yr
- 6 x likely to get pregnant by 18yr
- Risky behaviours – not wearing a seat belt, getting into fights, carrying weapons
- Increased hospitalization for substance disorders



Sweeting et al 1998  
Muniz-cohen et al 2010  
Wilcox et al 2010

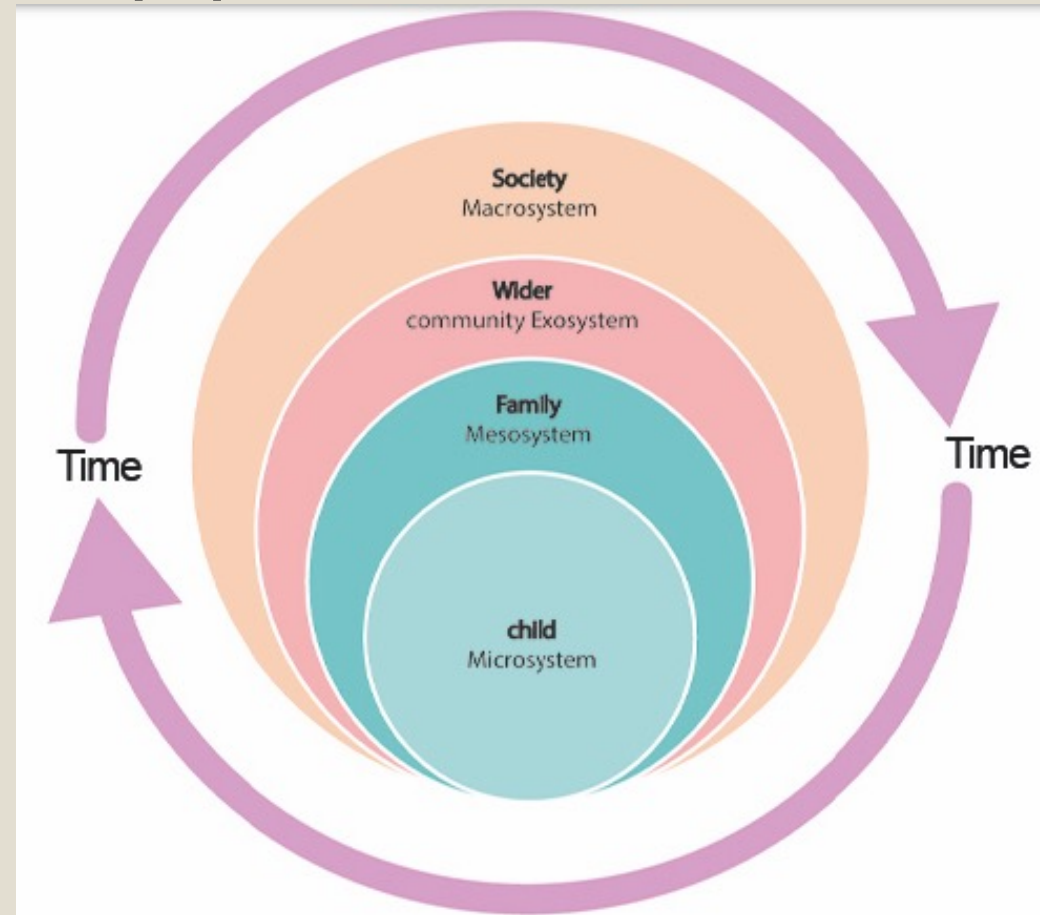
A photograph of an iceberg in the ocean. The tip of the iceberg is visible above the water surface, while the much larger, jagged base is submerged below. The water is a deep blue, and the sky is a lighter blue. The text is overlaid on the right side of the image.

**TAMARIKI/RANGATAHI  
GRIEF IS A  
PUBLIC HEALTH ISSUE  
EMERGENCY**

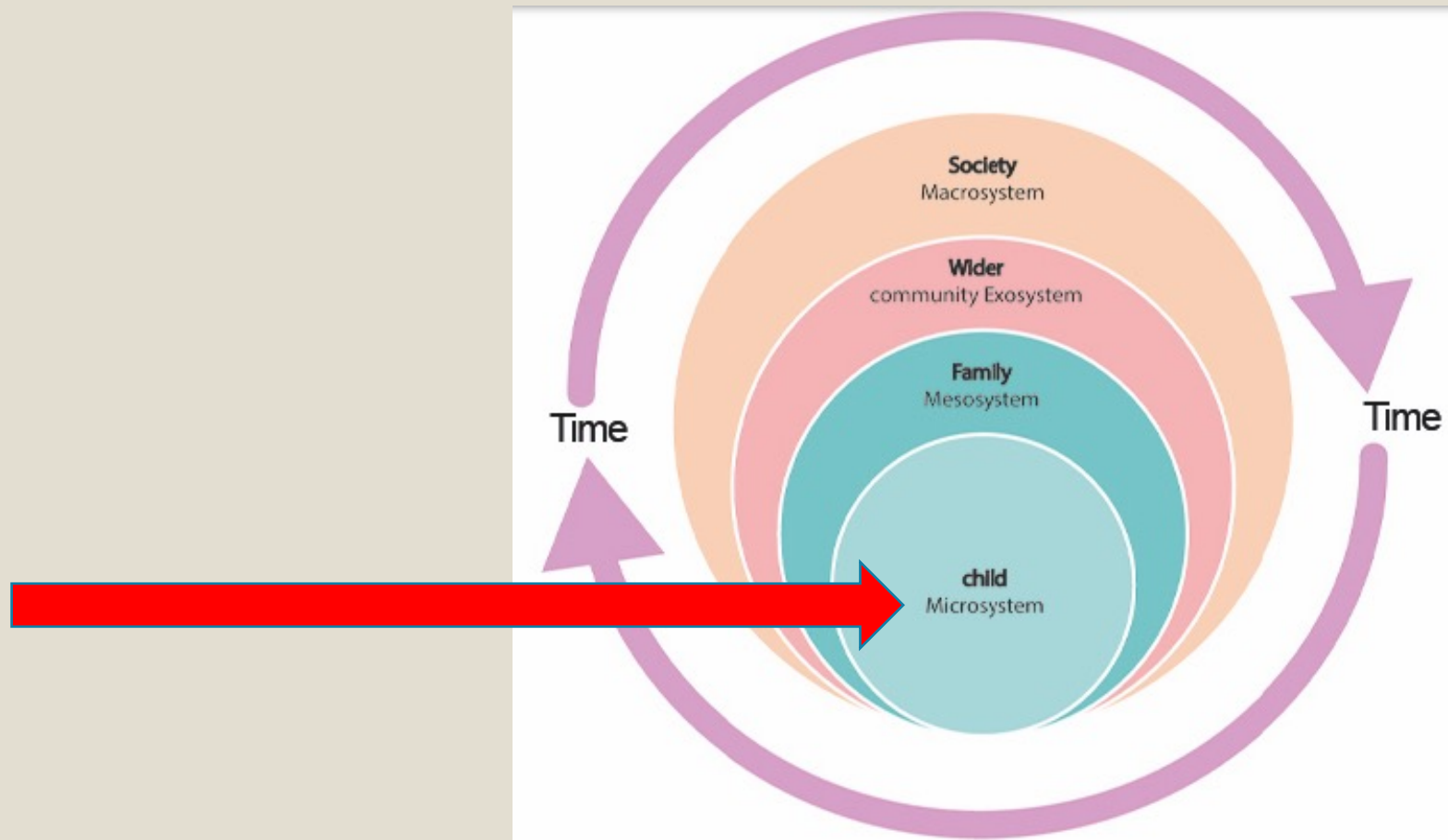
# Modifiable factors

- The death and the rituals surrounding it
- The relationship of the child with the deceased parent both before the death and afterwards
- The functioning of the surviving parent and his or her ability to parent the child
- Family influences such as size, solvency, structure, style of coping, support, and communication, as well as family stressors and changes and disruptions in the child's daily life
- Support from peers and others outside the family
- Characteristics of the child including age, gender, self-perception, and understanding of death.

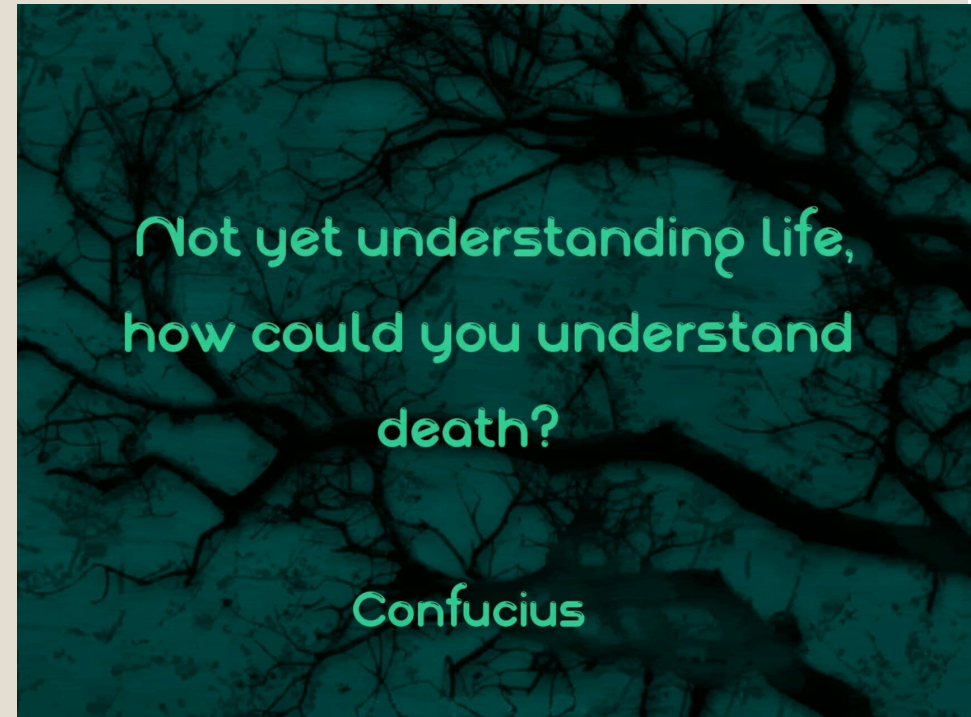
# My top tips in providing bereavement support.



# Tips: Focus on the child



# Tip: Learn Development



Webster, Skeen 2004  
Koocher 1974  
Cotton and Range 1990  
American Academy Paediatrics 2019

Tip: Learn to talk to kids



# Tip: Understand those with neurodiversity

Age	Developmental Stage (Piaget)	Perception or Concern	Anticipated Response
< 2 years	Sensorimotor	Sense separation and the emotions of others	Withdrawal Irritability
2 – 6 years	Preoperational	Dead = “Not Alive” Death as Temporary	Wonder about what the dead “do” Magical thinking (I am the cause)
6 – 10 years	Concrete operational	Morbid interest in death Others die → I die	Exaggerated behavioral reactions to the idea of death and dead things
Adolescence	Formal operational	Adult concepts Existential implications	“But not me” Death as an adversary



# Tip: Understand those with Neurodiversity

- Routines
- May not be able to imagine - may need physical proof
- Emotions – themselves and others
- Autistic traits increase
- Preparation essential for death/dying
- Language
- Funeral preparation – environment, food, social expectations

**Supporting children and young people with Autism Spectrum Disorder through bereavement**

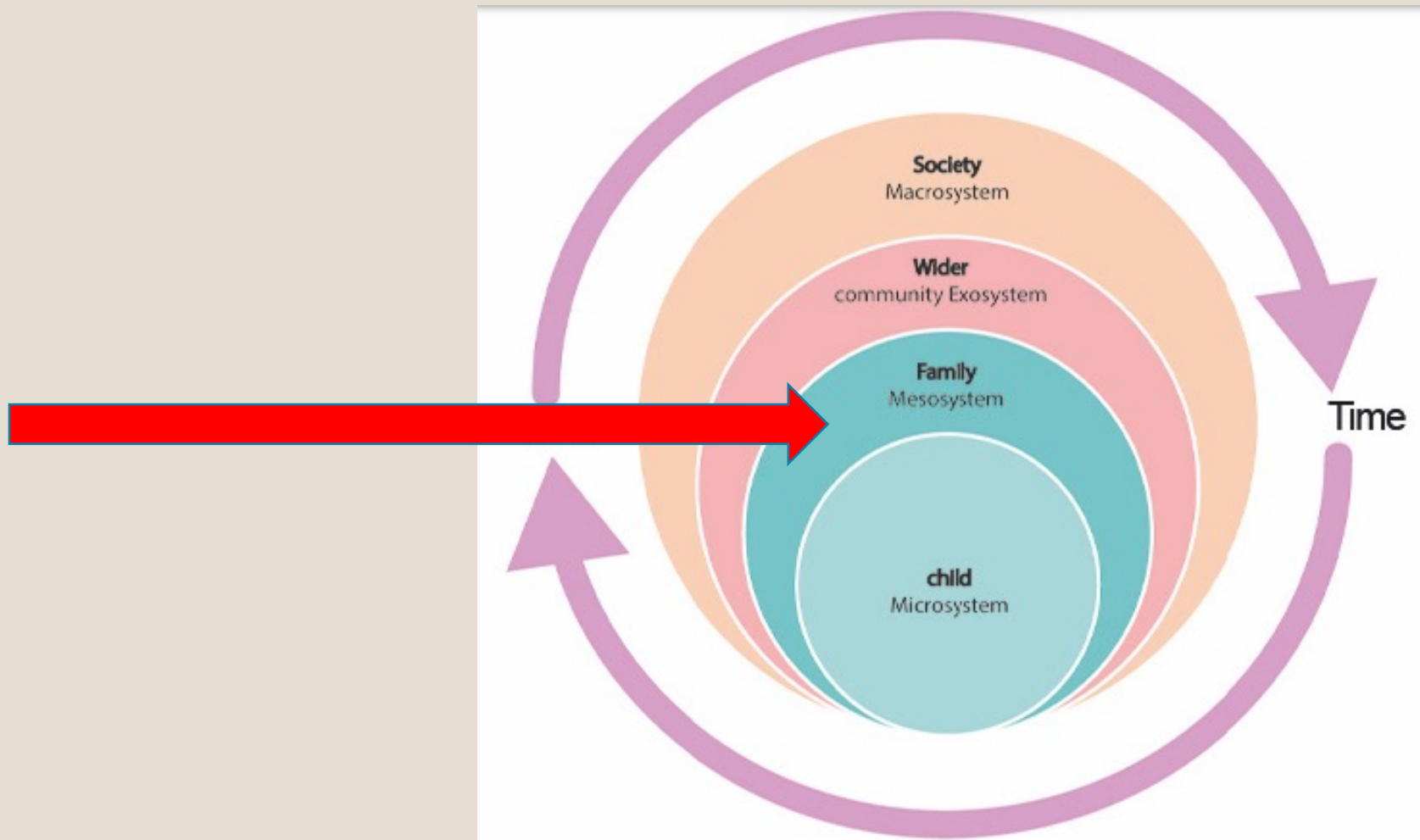
# Tip: Understand needs of LGBTQI youth



By: Rachel Melhorn, LCSW



# Tips: Focus on the parent





# Tip: Learn how to coach parents

## **Talking to tamariki** (children) **and** **mātātahi** (young people) **about** **terminal illness**

**A caregiver's guide**



## **About this guide**

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**This guide is a starting point for talking to your tamariki (children) if you or someone they love has mate pukupuku (cancer), or other serious illness, that has come back, spread or is terminal.**

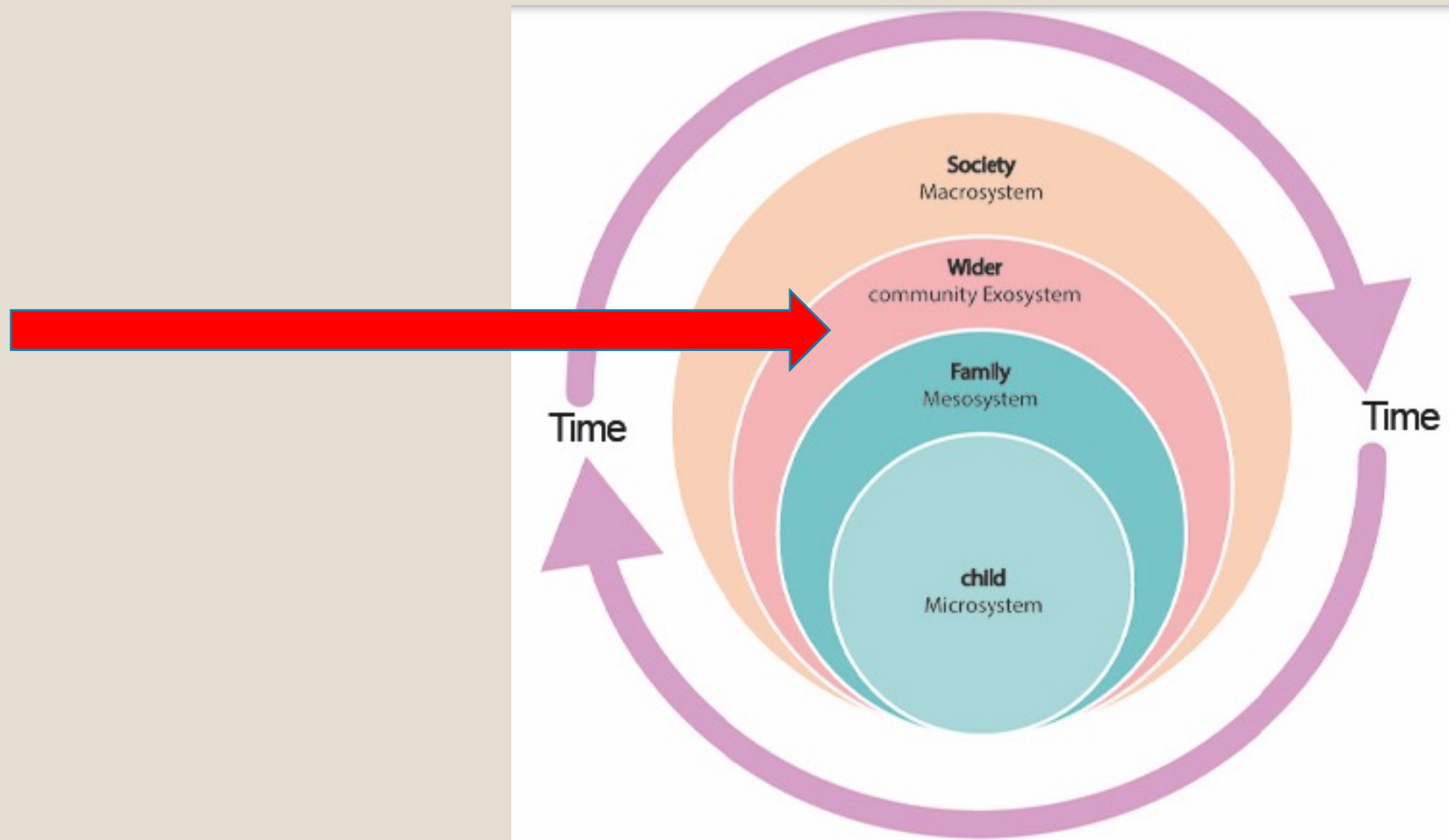
It'll help you understand how to talk sensitively and honestly about terminal illness with your tamariki, which can provide some much needed reassurance during this unsettling time.

# Tip: Use books as resources

1. The Invisible String
2. Something has happened (activity book, 3 – 6 years)
3. When tough stuff happens (activity book, 7 – 12 years)
4. Aroha's way
6. Grief is like a wave
7. The hug blanket, Chris Gurrey
8. No Matter What, Debi Gliori
9. Ida, Always
10. Search for the Lighthouse people
11. Kenzie's Gift Memory Kits



# Tips: Focus on school and community



# Tip: work with schools

> [Omega \(Westport\)](#). 2021 Feb 14;30222821993624. doi: 10.1177/0030222821993624.

Online ahead of print.

## "I Don't Know What to Say": Teachers' Perspectives on Supporting Bereaved Students After the Death of a Parent

[Inbar Levkovich](#)<sup>1</sup>, [Zohar Elyoseph](#)<sup>1</sup>

Affiliations + expand

PMID: 33583258 DOI: [10.1177/0030222821993624](#)

**How to support  
grieving tamariki**  
(children) **and**  
**mātātahi** (young  
people) **in kuranga**  
(education).

**A teacher's toolkit**

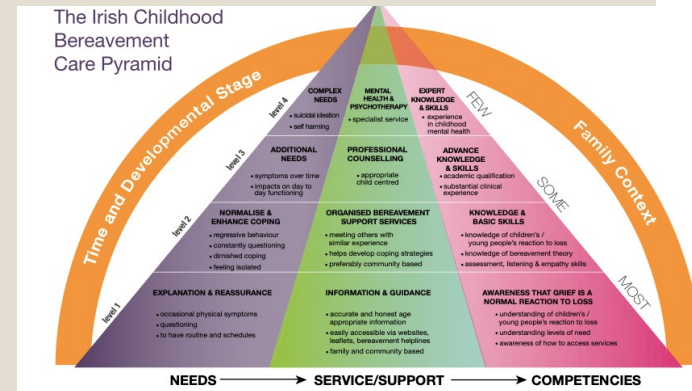


Kenzies gift



# Tip: Organisation changes

- Discuss children who will or are bereaved in MDT
- Keep the child down as Next of Kin
- Put the siblings/children into the patients care plan
- Provide regular education
- Become Child-Centred organisations
- Develop policies
- Develop standards

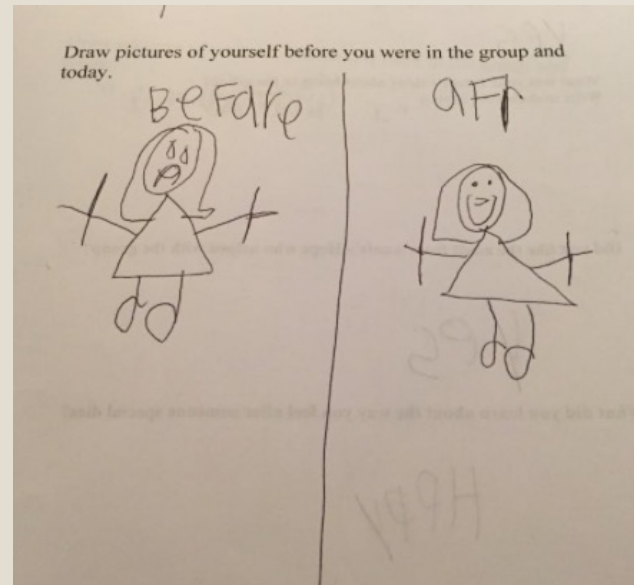


## The Standards

- Standard 1** **Child & Young Person:** Children's experience of bereavement will be recognised, acknowledged and supported in accordance with their needs over time.
- 
- Standard 2** **Family:** The family is generally the main source of care for the bereaved child and will require access to reassurance, information, guidance and support to provide this care.
- 
- Standard 3** **Local Community:** All bereaved children should have access to bereavement information, guidance and support services in their local community as required.
- 
- Standard 4** **Service Providers:** All service providers will ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care.
- 
- Standard 5** **National:** National policy and local infrastructure includes appropriate responses to, and integrates the needs of, bereaved children.

# Tip: Know your local resources

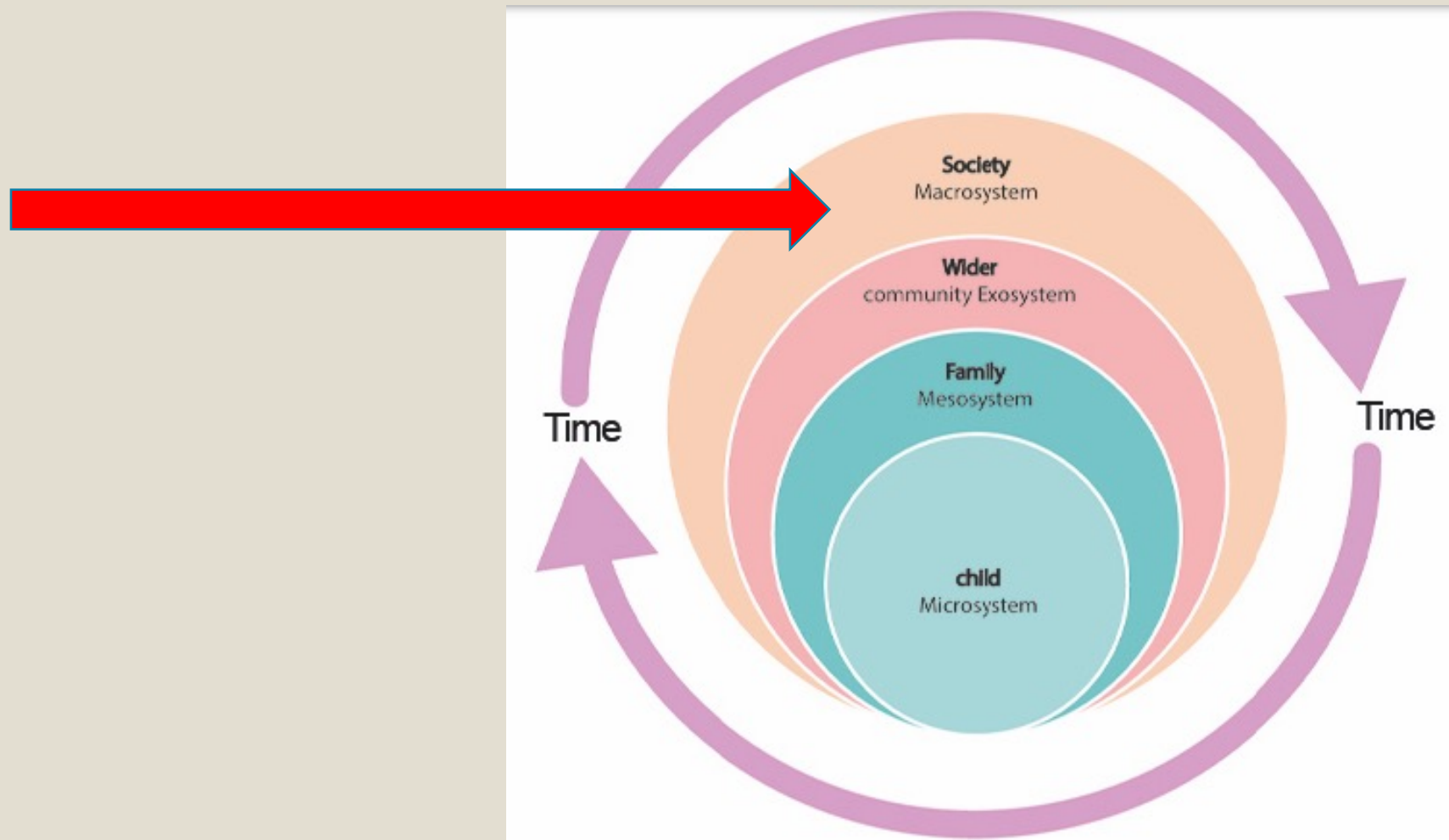
- CanTeen
- Kenzies Gift
- Skylight
- Grief Centre
- Traditional healers



- <https://www.canteen.org.au>
- <https://kenziesgift.com/grief-loss/memories-are-forever-packs/Skylight>
- <https://www.skylight.org.nz>
- <https://wheturangitia.services.govt.nz>
- Brake NZ



# Tips: Focus on societal need



# UN Convention on the Rights of the Child



## In Child Friendly Language

"Rights" are things every child should have or be able to do. All children have the same rights. These rights are listed in the UN Convention on the Rights of the Child. Almost every country has agreed to these rights. All the rights are connected to each other, and all are equally

### Article 12

You have the right to give your opinion, and for adults to listen and take it seriously.



### Article 13

You have the right to find out things and share what you think with others, by talking, drawing, writing or in any other way unless it harms or offends other people.

Children are our future Adults





*Surround yourself with people whose life was influenced by the person who died and let their stories influence your life today.*

*It's natural to worry about other family members – it's not your responsibility to minimise their grief, and accept the care they need – and grieving together can be a safe shelter from the storm.*

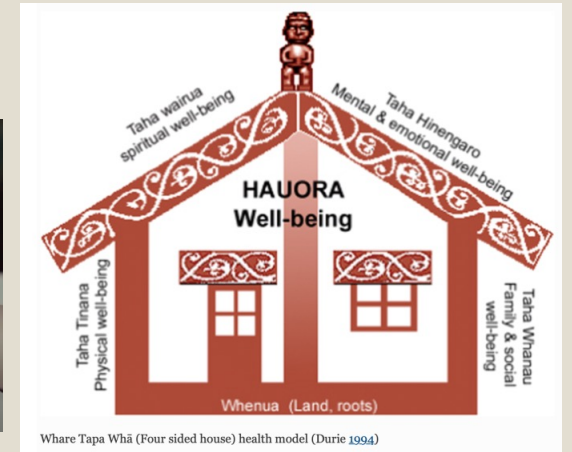
*... a memory box of things that remind you of the person who died.*

CAT WAS SIX WHEN

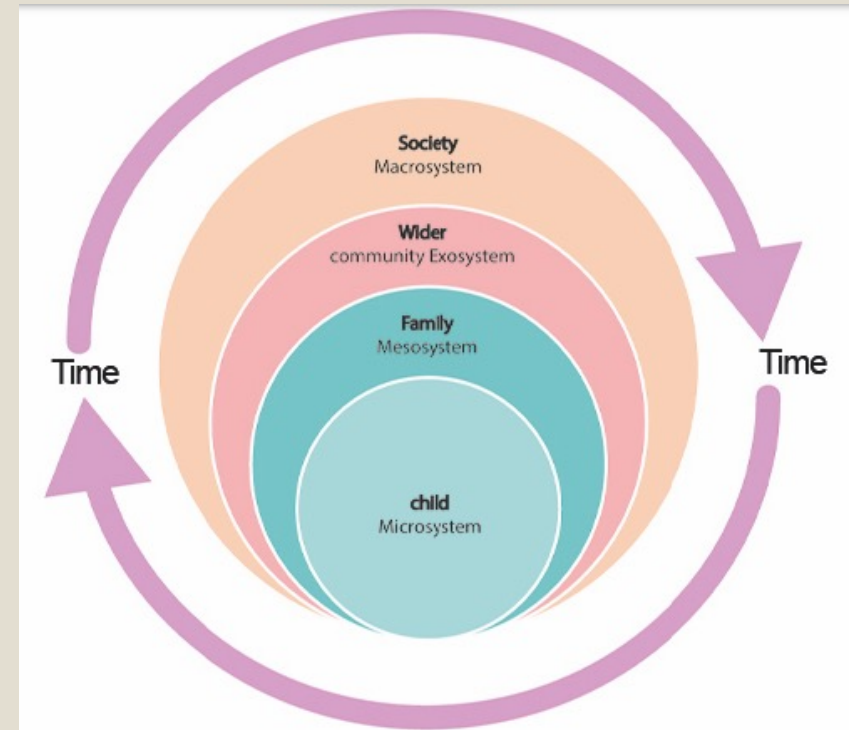
ALEX WAS 14 WHEN HIS DAD DIED

... WHEN HER MUM DIED

# My hope:



- Tamariki and Rangatahi grief is everyone's business
- Children will become visible in all aspects of our care in palliative care - personal and organization
- You will have tips to support children/parents/schools
- You will know where to access resources if you require them





Ahakoā whati te manga,  
e takoto ana anō  
te kōhiwi



Although the branch is broken  
off, the trunk remains

[Amanda.evans@marypotter.org.nz](mailto:Amanda.evans@marypotter.org.nz)

021973761