


## Wonders, Worries & Wishes: Talking with Children About Illness & Death

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## Objectives

- Reflect on the desire to *protect* children from death, and contrast that with the benefits of *preparing* them
- Address common myths that obstruct optimal support of children when someone is dying
- Examine principles of communicating with children about illness, dying and grief, and learn to respond to their common questions and concerns

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## Disclosures

- I have no financial disclosures
- The approaches and strategies shared are not my own
- I still find these conversations challenging and uncomfortable!

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## Who is this for?

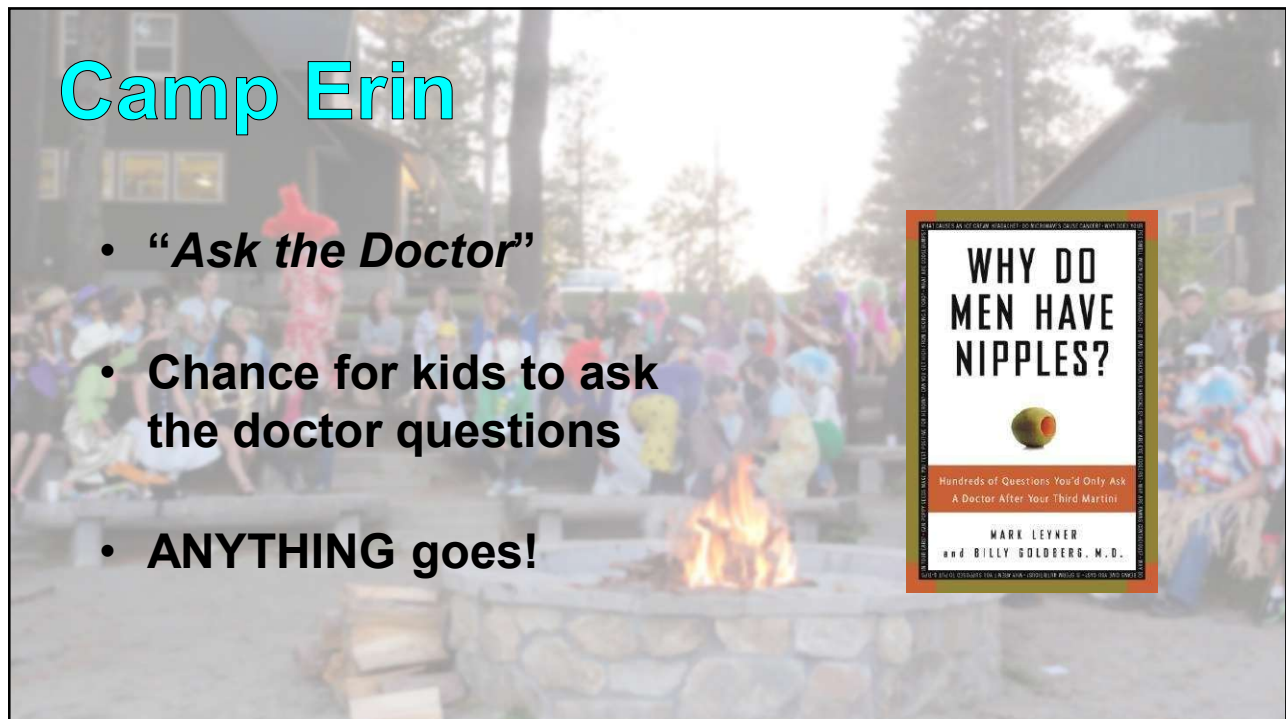
- Anyone who...
  - Works with seriously ill children
  - Works with siblings of seriously ill children
  - Works in adult palliative care
  - Has children of their own and might one day have to confront death or dying

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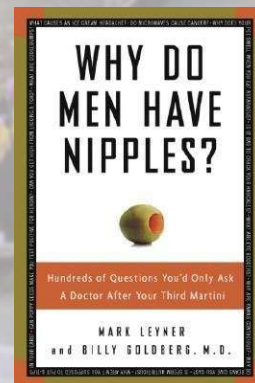
## Camp Erin

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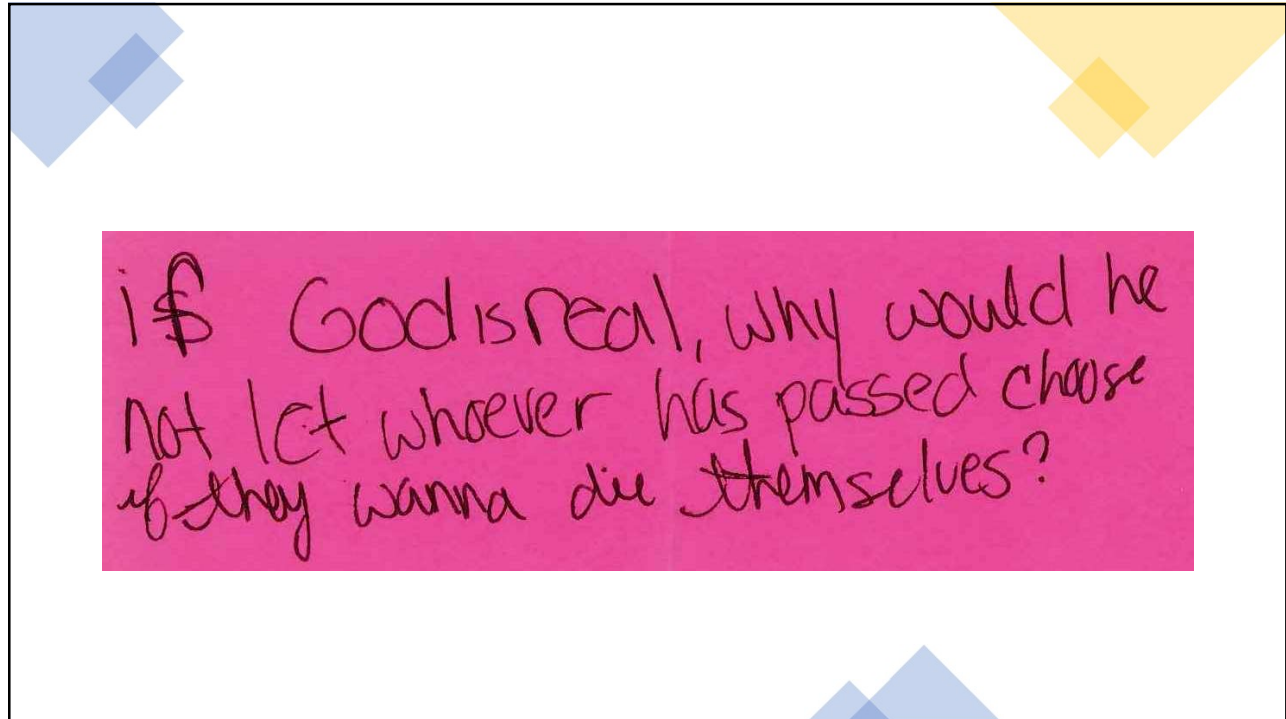


## Camp Erin

- ***“Ask the Doctor”***
- **Chance for kids to ask the doctor questions**
- **ANYTHING goes!**



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## Scope of the problem

- “1 in 5 children will experience the death of someone close to them by age 18” <sup>1</sup>
- Increased health risks associated with bereavement:<sup>2,3,4</sup>
  - Physical
  - Psychological

1. Kenneth Doka, Editor of OMEGA, Journal of Death and Dying

2. Stroebe M, Schut H, Stroebe W. *Lancet*. 2007 Dec;370(9603):1960-1973.

3. Jessop M, Fischer A, Good P. *Palliat Med*. 2022 Jun;36(6):928-937.

4. Ridley A, Frache S. *Palliat Med*. 2020 Dec;34(10):1340-1350.

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## Can the outcomes be altered?

### Bottom line:

**Any intervention that involves purposeful, open, honest and sincere communication will have a positive impact**

Ridley A, Frache S. Bereavement care interventions for children under the age of 18 following the death of a sibling: a systematic review. *Palliat Med.* 2020 Dec;34(10):1340-1350.

Bergman AS, Axberg U, Hanson E. When a parent dies - a systematic review of the effects of support programs for parentally bereaved children and their caregivers. *BMC Palliat Care.* 2017 Aug 10;16(1):39.

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## So many reasons NOT to talk about it



We need to protect children from emotional pain

If I tell them, they will think about it all the time

If a child isn't talking about it, neither should we

Some children do not wish to know the truth

They are too young

It's best to avoid the "D" word

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**MYTH:**

We need to  
protect children  
from  
emotional pain

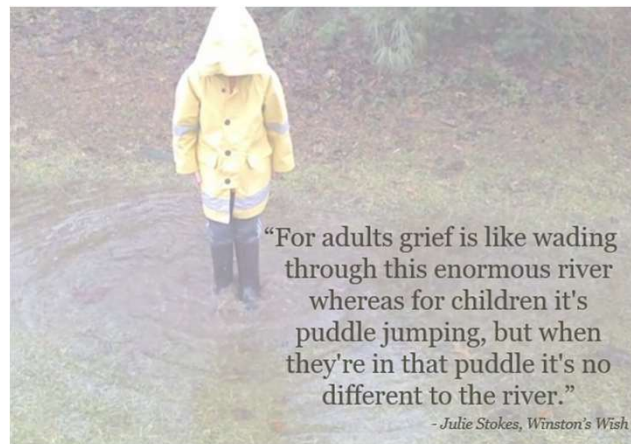


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**MYTH:**

If I tell them,  
they will think  
about it all the  
time



“For adults grief is like wading through this enormous river whereas for children it's puddle jumping, but when they're in that puddle it's no different to the river.”

- Julie Stokes, *Winston's Wish*

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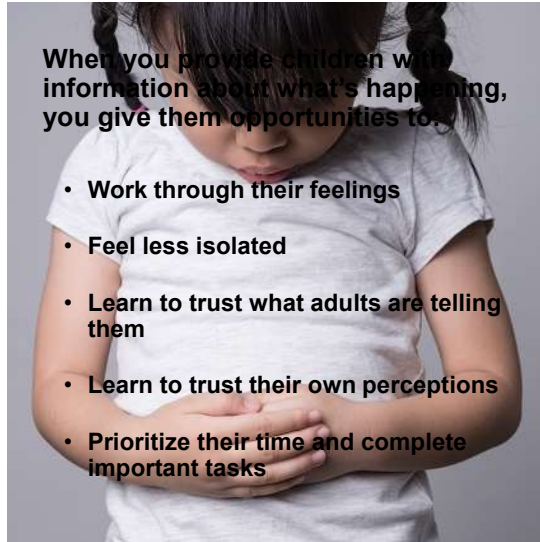
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**MYTH:**

**If a child isn't talking about it, neither should we**

When you provide children with information about what's happening, you give them opportunities to:

- Work through their feelings
- Feel less isolated
- Learn to trust what adults are telling them
- Learn to trust their own perceptions
- Prioritize their time and complete important tasks



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**MYTH:**

**Some children do not wish to know the truth**

**It's not a disclosure...  
it's a conversation**



It's the responsibility of adults to take the lead in opening conversations with kids

**Then...**

Let the child/youth take the lead in how much information she/he wants about the situation

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**MYTH:**

**They are too young**

**DEATH**

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**MYTH:**

**It's best to avoid the "D" word (or the "n" word)**

- Use accurate terms: "dead", "dying", "death"
- NOT: "sleeping", "passed away", or "gone to a better place"

**What does it mean to be dead?**

"When somebody dies, their body stops working and cannot start working again. Their heart stops beating and lungs stop breathing. The person cannot see, hear, smell, think, or feel anymore"

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# Answering Children's Questions

A 3-Step Guide



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## Key principles

- Use simple, but correct language
- Be honest!
- It's ok to say "*I don't know*"

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## Conversation openers

- Start by asking what the child understands about the situation
- Explore if they've overheard anything that they don't understand
- Encourage them to ask questions or share concerns...all are ok!

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## The answering part

### 1. Validation

- Praise
- Repeat
- Use child's words

"That's a great question"

"Boy, that's a hard one!"

"Very Interesting..."

Thompson F, Payne S. Bereaved children's questions to a doctor. *Mortality*. 2000;5(1):74-96.

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## The answering part

### 2. Reflection

- Explore...
  - Thoughts
  - Feelings
  - The question behind the question

“What do you think?”

“Is that something you’ve been worried about?”

“Can you tell me more about why you’re asking?”

Thompson F, Payne S. Bereaved children's questions to a doctor. *Mortality*. 2000;5(1):74-96.

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## The answering part

### 3. Description

- Explain
  - Facts
  - Language
- Address misconceptions



Thompson F, Payne S. Bereaved children's questions to a doctor. *Mortality*. 2000;5(1):74-96.

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## How to talk about illness



- Name and describe the illness
- Describe treatments that were tried
- Describe signs/proof of disease progression

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## The 6 C's & the 3 W's



Addressing the most common and most important concerns

(even when they're not endorsed)



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# The 6 C's

What's it **CALLED**?

Did I **CAUSE** it?

Can I **CATCH** it/give it to others?

Can I **CURE** it?

Who will take **CARE** of me?

Will I always be **CONNECTED** to the people I care about?



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What's it **CALLED**?

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Did I **CAUSE** it?

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Can I **CATCH** it?

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Can I **CURE** it?



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Who will take **CARE** of me?



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Will I always be **CONNECTED** to the people I care about?



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# The 3 W's

Wonders

Worries

Wishes



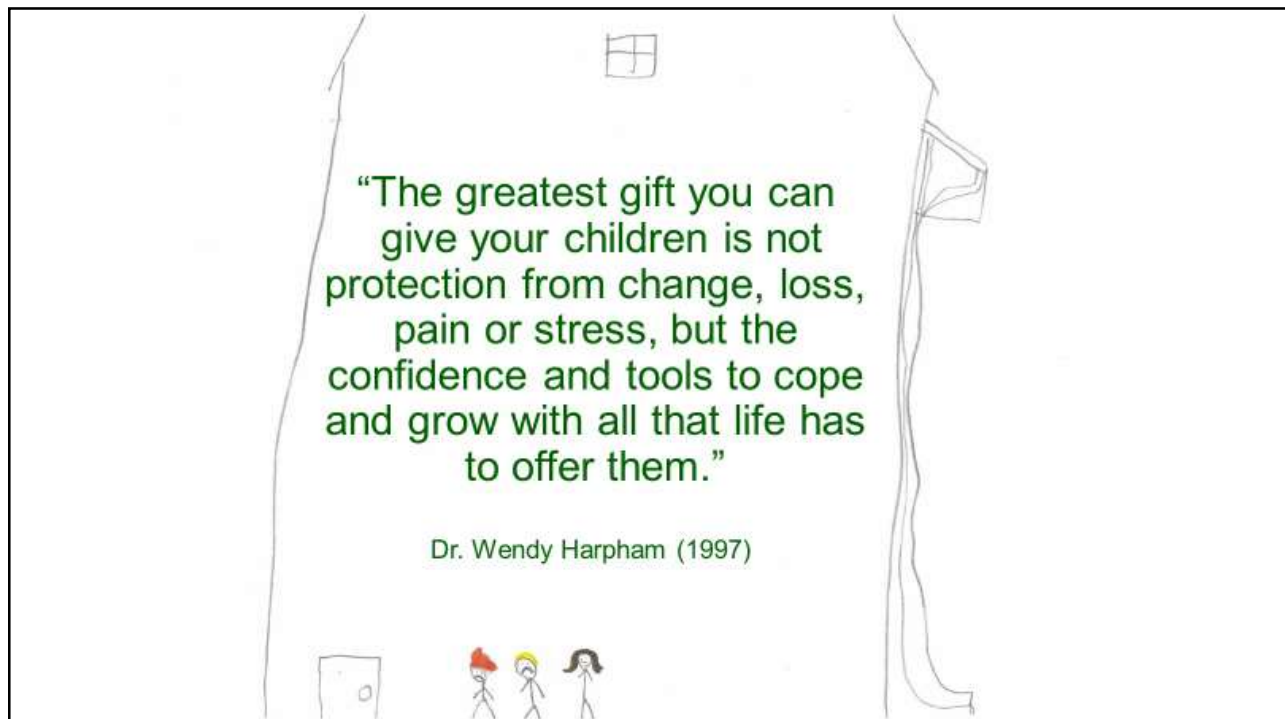
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## Take home messages

- Kids cope better with (honest) information
- DON'T force talking about death, but DO provide opportunities
- **Remember:** address the 6 C's and explore the 3 W's



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