

"What About Me?"

Including children when a family member is dying

MOUNT SINAI HOSPITAL 

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MOUNT SINAI HOSPITAL
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Learning Objectives

- To explore young people's perspectives and experiences someone is dying, in order to:
 - Support and guide caregivers through the process of communication with children;
 - Identify needs and opportunities to prepare and include young people at the bedside; and,
 - Gain familiarity with creative strategies to help families maintain meaningful interactions and connections at the end of life.

MBWCC's approach

- Cannot avoid suffering – CAN build resilience;
- Move from protect to prepare & take care;
- Grief needs “doing” not “fixing”;
- Old enough to be affected by death = old enough to be included and supported.



“Expose” vs. “Include”

“They’re better off not being here and seeing this.”

“It will be awful for them.”

Preparing kids and teens

- Explain what they will see, hear & smell, patients, staff, precautions, equipment, behavior, rules, etc.



- ALL feelings are ok even if some behaviors aren't
- Who to ask for help, where to go for a 'break'?

What to Say, Where to Start...

- Ask what they know so far. Clarify.
- Encourage kids to ask questions or worries
 - Reassure that all are ok
 - Avoid minimizing fears or concerns
- Answer honestly, be clear and concrete.
- When you don't have an answer, say so.



About the illness...

- Name & describe illness -
say “cancer” & “tumor” *not* “sick” or “bump”
- “Nothing you (or anyone) could have done to cause, avoid or cure it.”
- Reassure that they can’t ‘catch’ it.
- Describe treatments.
- Describe signs/proof of progression.



About dying...

- Explain that medicine can still provide comfort – “feel better” vs. “get better”.
- Do say “going to die”
- Do *not* say:
 - “nothing more we can do”
 - “not going to get better”
 - “gone”, “lost”, “passed away”, or “in heaven”.



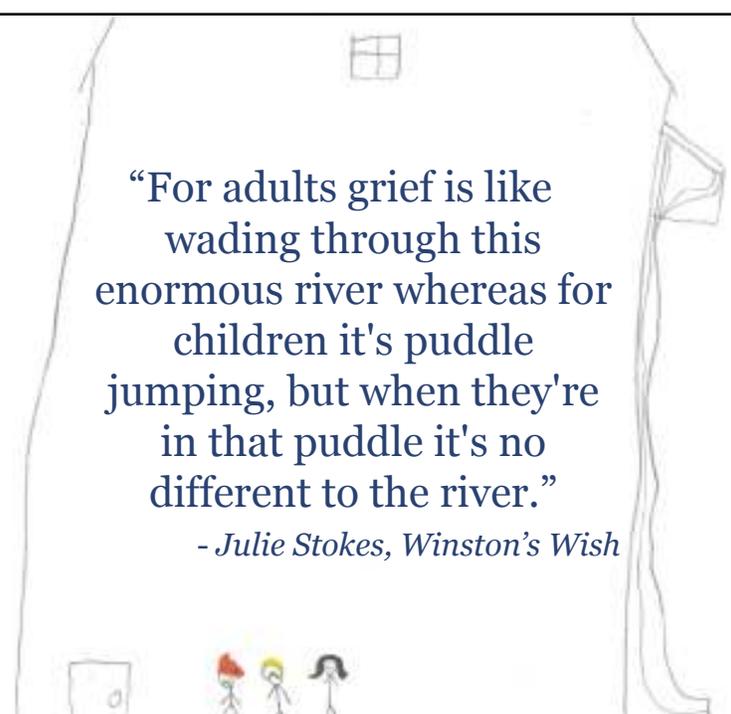


Most importantly...

- The 3 C's:

- Did I **CAUSE** it?
- Can I **CATCH** it?
- Who is going to take **CARE** of me?

Death does not end relationships.
Although changed, they are
meaningful and real.



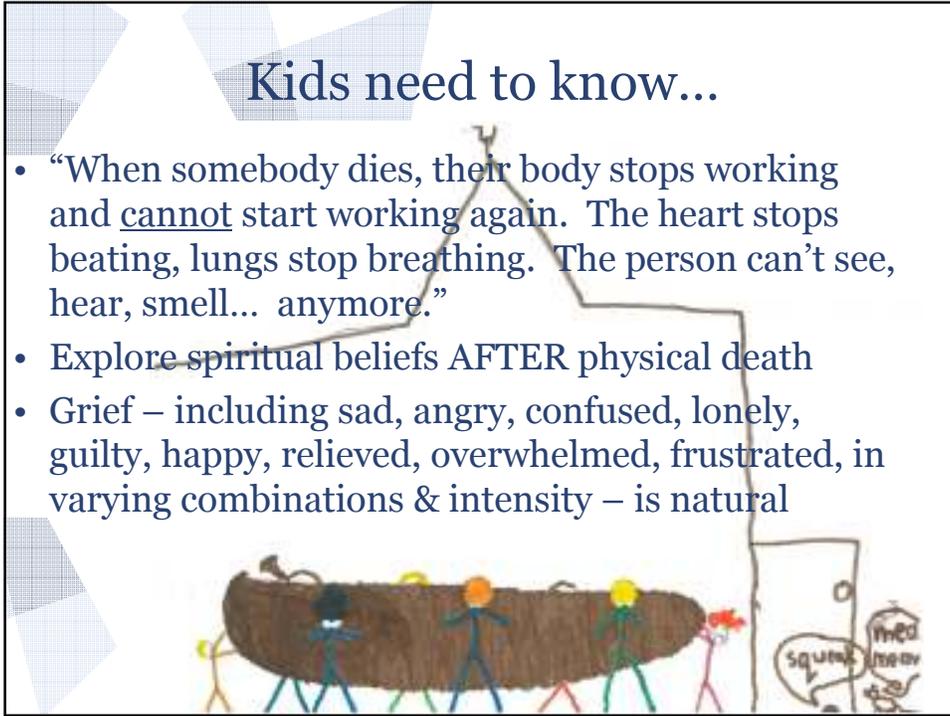
“For adults grief is like
wading through this
enormous river whereas for
children it's puddle
jumping, but when they're
in that puddle it's no
different to the river.”

- Julie Stokes, *Winston's Wish*



Kids need to know...

- “When somebody dies, their body stops working and cannot start working again. The heart stops beating, lungs stop breathing. The person can’t see, hear, smell... anymore.”
- Explore spiritual beliefs AFTER physical death
- Grief – including sad, angry, confused, lonely, guilty, happy, relieved, overwhelmed, frustrated, in varying combinations & intensity – is natural



How kids grieve

- No ‘order’, unpredictable, no age rules
- In chunks – “feeling span”, balance grief & play
- Over time - changes with new understanding, not “regression,” progress on a bumpy road.
- “Feed the need” -
expression, security,
control, familiarity,
identity & meaning
making.



“Feed the need”

- Fear of unknown → Feeling prepared
- Helpless → Having a role
- Responsible → Understanding
- Vulnerable → Supported, connected
- Different / alone → Included
- Chaotic → Secure, some control

How to help

Children need extra, not different support when someone is dying or has died:

* **Love** * **Inclusion** * **Support**

1. Discuss, encourage and model expression of **ALL** emotions, in a range of healthy ways
 - a) feelings vs. behaviors
 - b) don't force talking

2. Balance consistency and needs to adapt
consistent/predictable/familiar = security, control
3. Create rituals & ongoing opportunities for:
support, emotional expression & care,
maintaining connection, meaning-making



Including kids

- bring special items from home;
- talk, read, sing or chose music;
- lotion, mouthcare, nailpolish, warm/cool cloths;
- decorate blankets & pillowcases;
- decorate room, etc.
- watch movies together... just “be”



Including kids

- Legacy creation:
 - stories, journals, memory book,
 - photos, video,
 - hand prints, memory bracelets,
 - clothes,
 - anything created through caregiving roles, etc.

“A child can live through
ANYTHING, so long as he or she
is told the truth and is allowed to
share with loved ones the natural
feelings people have when they
are suffering”

(LeShan, 1976)

Literary Resources for Adults

Eaton Russell, C. (2007). *Living Dying: A Guide for Adults Supporting Grieving Children and Teenagers.*

Hamilton, Joan. (2001). *When a Parent is Sick. Helping Parents Explain Serious Illness to Children.*

Lowenstien, L. (2006). *Creative Interventions for Bereaved Children.*

Silverman, P. R. (1999). *Never Too Young to Know: Death in Children's Lives.*

Worden, W. (1996). *Children and Grief: When a Parent Dies.*

Literary Resources for Children

Brown, L. K. (1996). *When Dinosaurs Die: A Guide to Understanding Death.*

Goldman, L. (2005). *Children Also Grieve: Talking about Death and Healing.*

Mellonie, B. (1983). *Lifetimes: A Beautiful Way to Explain Death to Children.*

Paterson, K. (1977). *Bridge to Terabithia.*

Schweibert, P., & DeKlyen, C. (1999). *Tear Soup: A Recipe for Healing After Loss.*

White, E. B. (1974). *Charlotte's Web.*

Web Resources

Association for Death Education and Counselling:
www.adec.org

Dougy Centre: www.dougy.org

Grief Works BC: www.griefworksbc.com

Kids Help Phone: www.kidshelpphone.ca
(1-800-668-6868)

Mind Your Mind: www.mindyourmind.ca

Soul2Soul: www.soul2soul.ca

Paper Flower Pots: www.geocities.com/newspaperpots/

Winston's Wish: www.winstonswish.org.uk