

The Dying Parent and their Child: Strategies for Professional Leadership When Everyone is “Lost”

MOUNT SINAI HOSPITAL



MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex

Temmy Latner Centre for Palliative Care

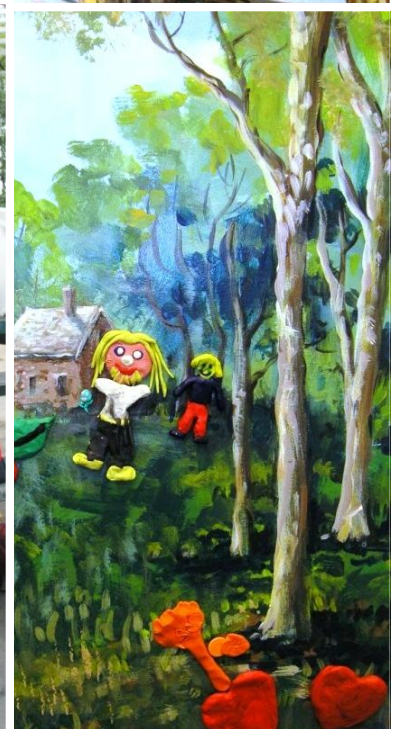


Andrea Warnick, RN, BScN, MA
andrea.warnick@tlcpc.org

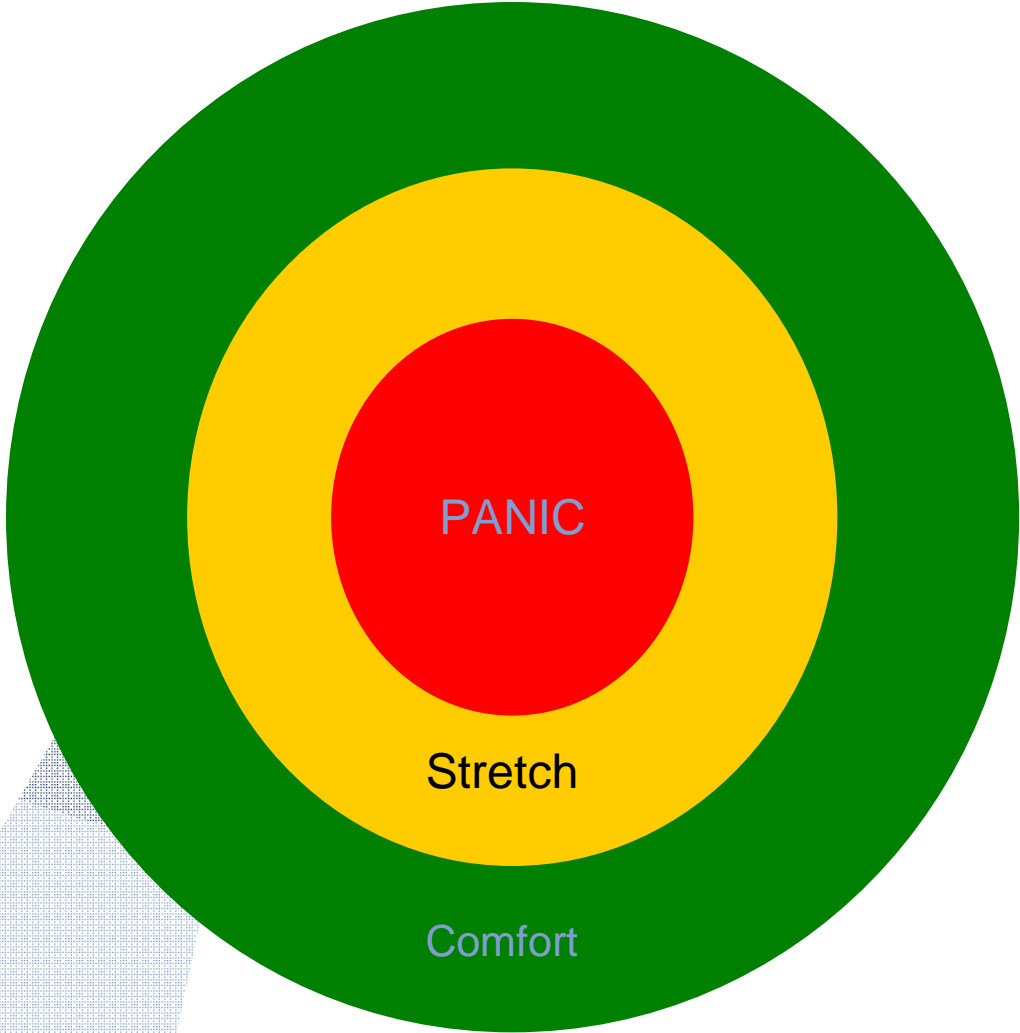
Max and Beatrice Wolfe Centre
for Children’s Grief and Palliative Care

Objectives

1. Identify common barriers regarding talking to children and adolescents about death.
2. Recognize and learn from children's and adolescents' extraordinary capacities to understand, and live with issues related to dying and death.
3. Identify strategies and interventions to facilitate communication among family members when a parent is dying.



The Zone



What the Research Says

- “It is becoming clear that children’s levels of anxiety are related to whether they are told about the illness and to the quality of the communication with their parents.”
(Kroll et. al., 1998)
- When children are not given accurate information, they will create information to complete the story (M. Riely, 2003)

What the Research Says Cont...

- Professionals are often inhibited by their anxieties about saying or doing the wrong thing and causing lasting emotional damage (C. MacPherson, 2005)
- Parents appear to be unaware of significant emotional & behavioral problems experienced by their children . . . Health professionals may need to assist parents in recognizing & coping with their children's distress when it is present (A.S. Welch, M.E. Wadsworth & B.E. Compass, 1996)

What the Children Say

- No one told me he was dying, but I could see; he was wicked skinny . . .

Andrew, aged 12

- It was easier for us not to have to imagine what was happening. That would have been worse.

Luke, aged 17

- [My mom] told me she would tell me whatever she knew, and I wasn't as scared.

Ben, age 9

- We came to see him just before he died, so we were there. I was scared, but I was glad, too, that I was there.

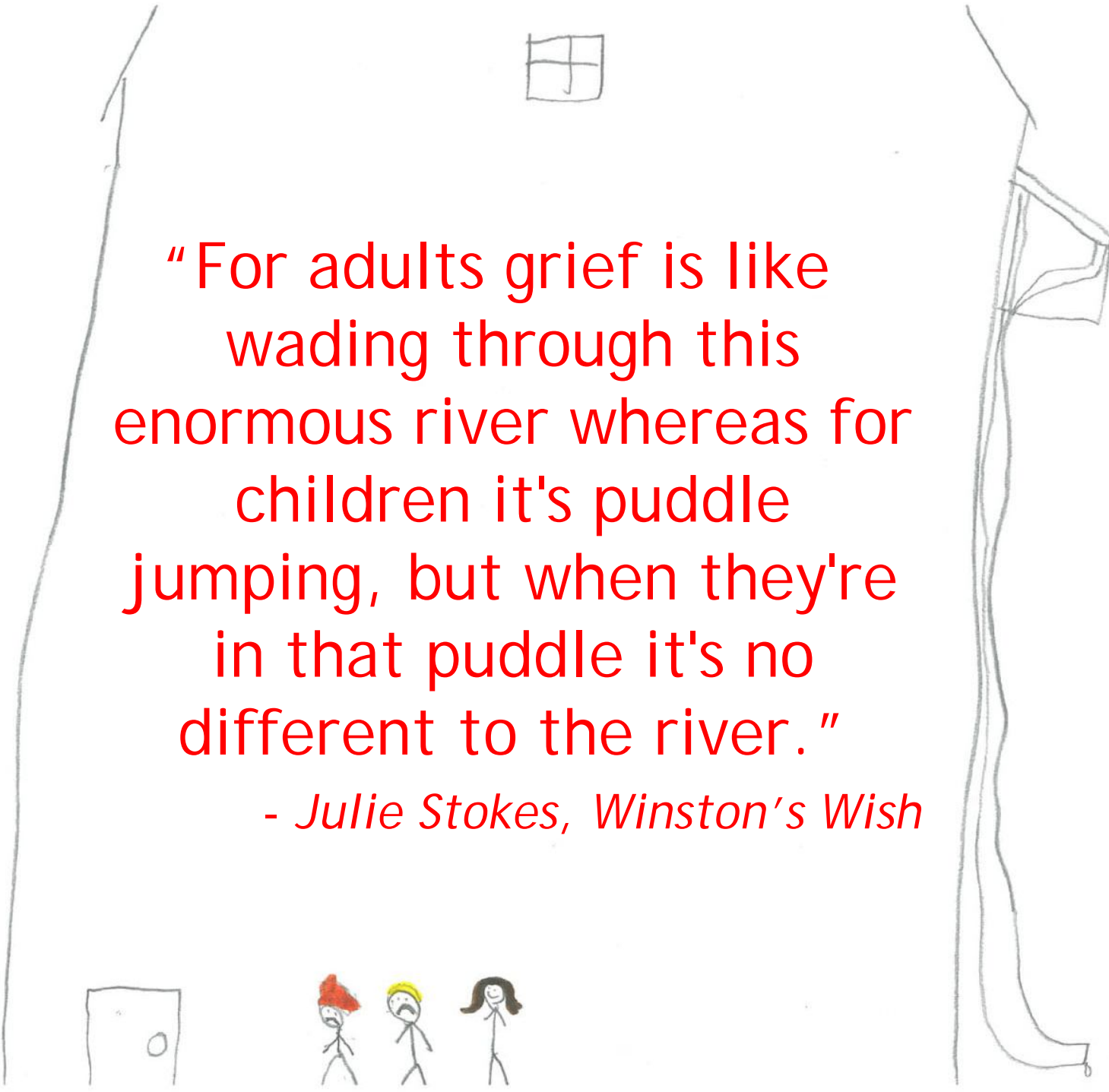
Christian, aged 11

Myths and Misconceptions

- The child does not know
- The child is too young
- If the child isn't talking about it neither should we
- It's better to say nothing than the wrong thing
- There will be a "right" time
- Children should not be at the bedside of the dying
- We need to protect the child
- It's better to wait until death is certain
- The child will think about it all the time

How Kids Grieve





"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*

OVERVIEW OF A CHILD'S UNDERSTANDING OF DEATH

- **< 2 Years:** No real concept (but still react to separation).
- **3-4 Years:** Death is a changed state. Doesn't understand finality. Often believe death is accidental rather than inevitable.
- **5-6 Years:** Grasp many components of a mature concept of death, such as finality and nonfunctionality, but do not recognize personal mortality.
- **9-10 Years:** Full understanding of all components of death.

The 3 C's of What Children Want to Know

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

Preparing Kids...

To visit a patient, hospital or go to a funeral

- Explain what they will see, hear and smell, people's behavior, any 'rules'
- Books
- ALL feelings and reactions are 'okay'
- Model grief
- Help kids find meaningful, age-appropriate ways to interact and 'caretake'. Invite to join rituals.

Kid-Friendly Explanations

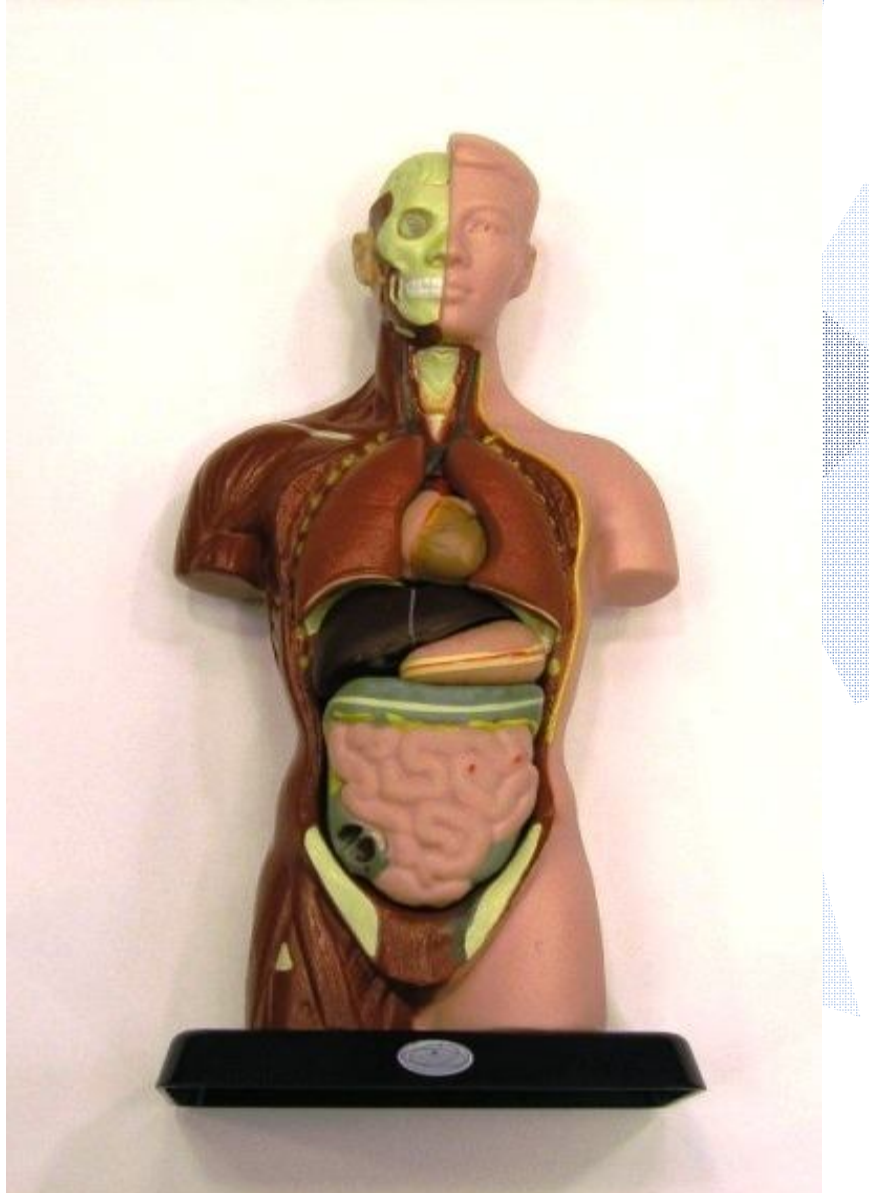
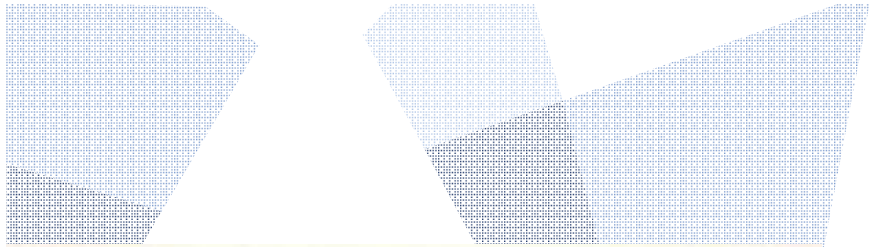
- “DEAD” means that a body has stopped working and will never work again. The body cannot move, breathe, think, feel, see, smell, talk... The body does not feel pain or hunger or fear.
- “CREMATION” is when a dead body is put through very high heat causing it to break down into small pieces (looks like sand/dirt).
- “GRIEF” is all the different feelings that occur when someone you care about is dying or has died (sad, mad, confused, worried, abandoned, happy, lonely, etc...)

What to Say, Where to Start...

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

About the Illness...

- Name and describe the illness and its' origin - it is not their fault.
- Address 3 C's
 - Reassure that they can't 'catch' it.
 - "There is nothing you could have done to cause, to avoid or to cure it."
- Help find ways to interact & "be" with parent.
- Describe treatments that were tried.
- Describe signs/proof of disease progression.



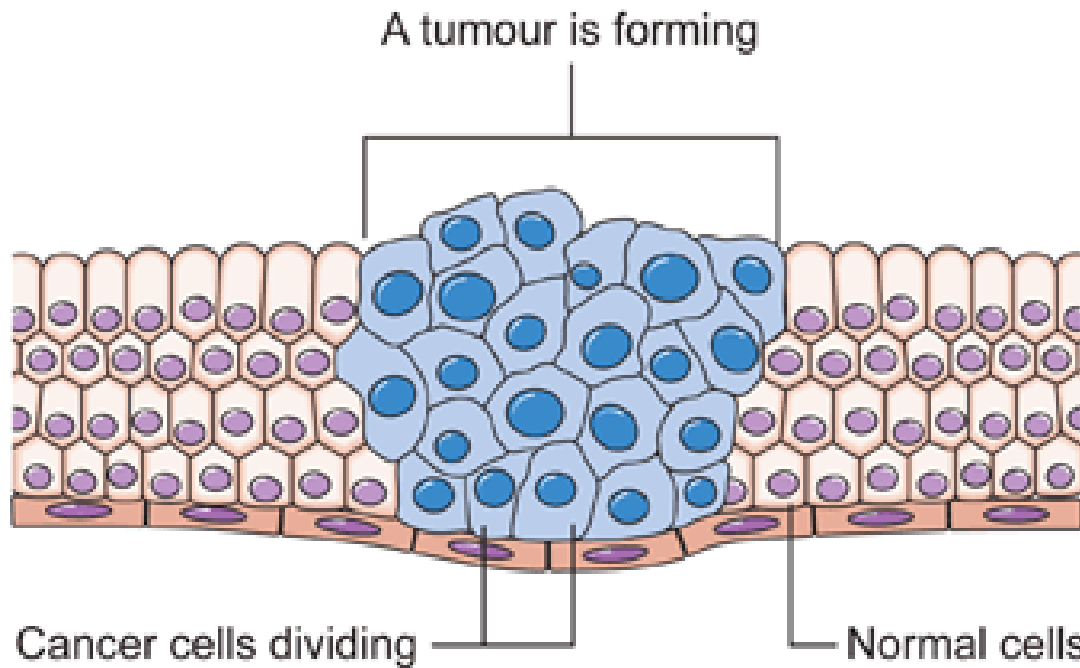
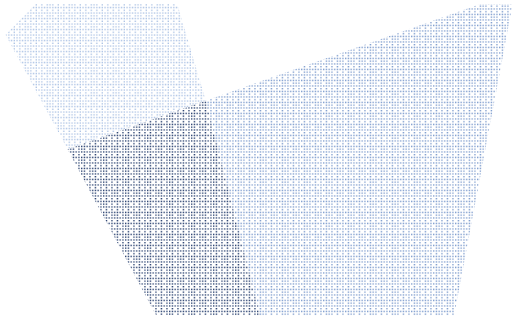
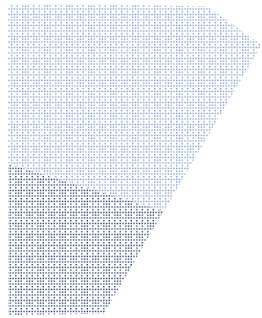
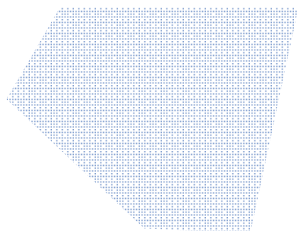
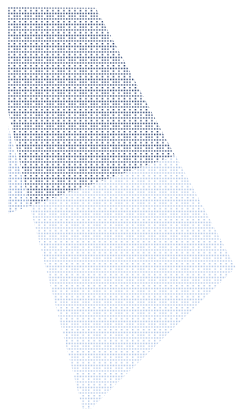


Diagram showing how cancer cells keep on reproducing to form a tumour
Copyright © CancerHelp UK



About Dying...

- Explain that medicine can still help the person be comfortable.
- Ask if want to know what to expect as person gets closer to dying?
- Clearly say “going to die”, “Not going to get better” is not the same thing.
- Wonder together.
- Even though the person is dying,

*They still care about the child
They will still be a part of the family*



The 3 C's of What Children Want to Know

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

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*.

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.*

Lowenstein, Liana. (2006). *Creative Interventions for Bereaved Children.*

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

The Dougy Centre (2004). *35 Ways to Help a Grieving Child.*

The Dougy Centre (2004). *Helping Teens Cope with Death.*

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

Web Resources

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

Canadian Virtual Hospice: www.virtualhospice.ca

Dougy Centre: www.dougy.org

Grief Works BC: www.griefworksbc.com

Hospice Calgary: www.hospicecalgary.com

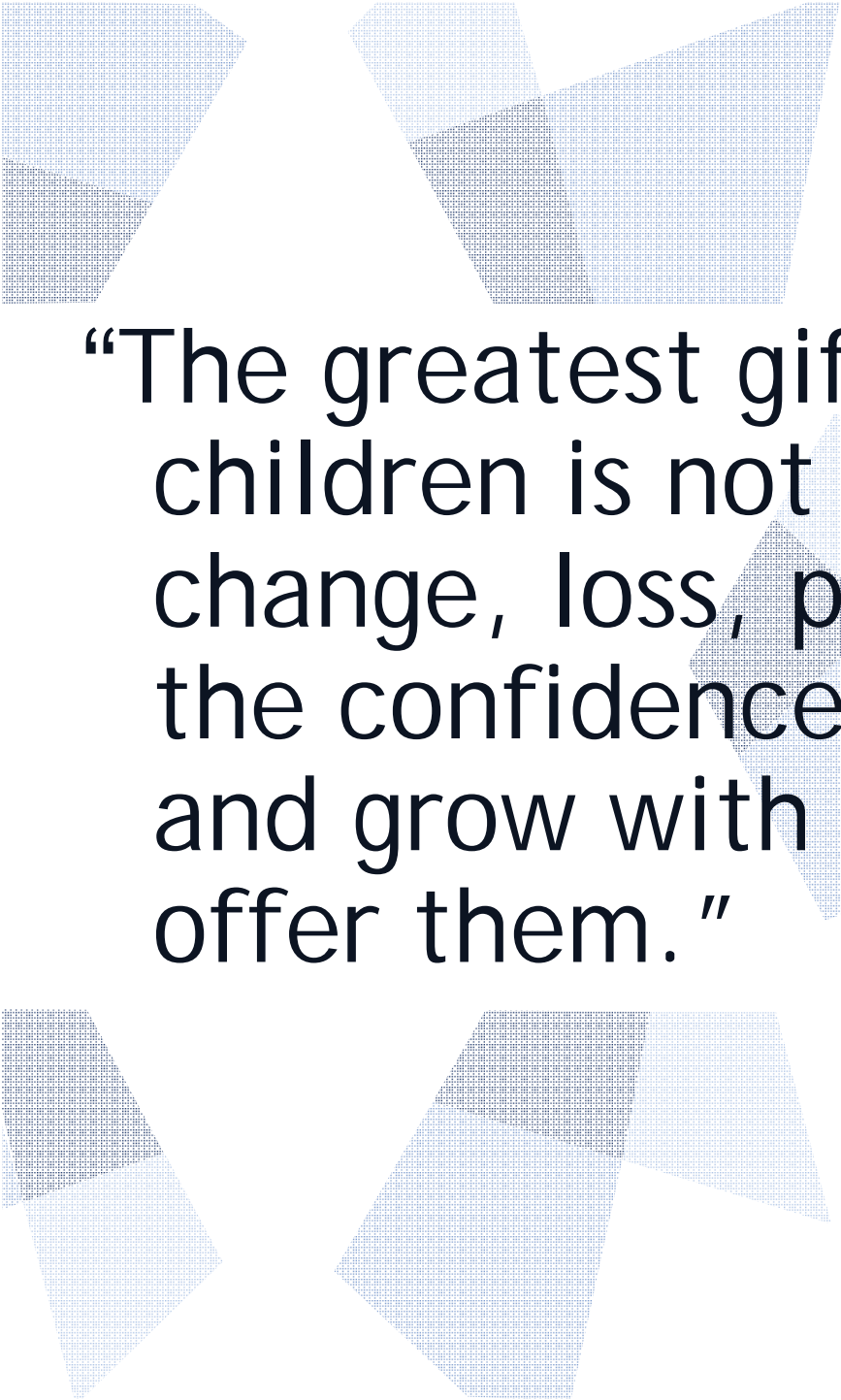
Kids Help Phone: www.kidshelpphone.ca
(1-800-668-6868)

Mind Your Mind (teens): www.mindyourmind.ca

Soul2Soul (teens): www.soul2soul.ca

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

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



“The greatest gift you can give your children is not protection from change, loss, pain or stress, but the confidence and tools to cope and grow with all that life has to offer them.”

Dr. Wendy Harpham

Reference List

Kreichbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J., & Steineck, G. (2004) Talking about death with children who have severe malignant disease. *The New England Journal of Medicine*, 351(12): 1175-1186

Kroll, L., Barnes, J., Jones, A.L. & Stein, A. (1998). Cancer in parents: telling children. *British Medical Journal*, 316: 880

MacPherson, C. (2005). Telling children their ill parent is dying: a study of the factors influencing the well parent. *Mortality* 10(2): 113-126

Riely, M. (2003). Facilitating children's grief. *The Journal of School Nursing*, 19(4): 212-218

Robinson, C. & Janes, K. (2001). "Is my mom going to die?" Answering children's questions when a family member has cancer. *Canadian Oncology Nursing Journal*, Nov: 62-66

Saldinger, A., Cain, A.C., Porterfield, K. & Lohnes, K. (2004). Facilitating attachment between school-aged children and a dying parent. *Death Studies*, 28(10): 915-940

Welch, A.S., Wadsworth, M.E. & Compas, B.E. (1996). Adjustment of children & adolescents to parental cancer. *American Cancer Society*, 77(7): 1409-1418