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Talking with Children About Serious Illness, Dying and Death

By Annie Leong, Palliative Care Nurse Consultant

Talking with children/youth about the serious illness, dying or death of someone close to them can seem overwhelming. Adults, parents/caregivers and family members who may be grieving themselves naturally want to shield children from the emotional pain of losing loved ones⁴. Often adults' first instincts are to protect children from the harsh realities of illness and death by withholding information and hiding their grief emotions. Grieving children, however, often need significant adults in their lives to provide honest information and model healthy ways of grieving.

This article offers health care providers some key strategies to help adults/caregivers talk with children/youth in a way that is open, honest, timely and age-

appropriate³ when someone they care about is ill, dying or has died.

1. Telling children – is never “too early” or “too young”

- Starting difficult conversations is never “too early” as it allows children to process their thoughts and feelings and to ask questions in the presence of caring and supportive adults in their lives⁵.
- Children are never “too young” for truth-telling. This sets the stage for openness and inclusiveness within a safe and nurturing environment.

2. “Before you tell, ask”

- Begin by asking what the child already knows, has seen or heard³. Clear any misconceptions they may have from overheard conversations.
- Give the information they need to know or ask for in “bite-sized” pieces.
- Look for cues to gauge how much detail to pro-

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vide and when the child is ready to hear or take a break.

- Some helpful conversation starters include drawing from the child's awareness of death through life experiences; e.g., seeing a family pet or farm animal dies or death portrayed in storybooks and movies.

3. Be open and honest

- Children typically know more than adults realize⁵. They can usually sense from their emotional surroundings that something is wrong.
- When shielded from the truth, children are likely to hold the question, become anxious, and may rely on overheard conversation or active imagination to make up their own explanation.
- Encouraging the important adults in their lives to share honest information and invite questions can help to build trust and enable children to cope better with difficult situations.
- It's okay to say, "*I don't know.*" Children often may not be looking for answers nearly

as much as they are seeking validation that adults too may not have all the answers to "life mysteries" relating to death and the afterlife. Support the child's curiosity by exploring these mysteries together and sharing family's values and beliefs that may provide comfort¹.

4. Use the "D" words: dying, died and dead

- Grown-ups often avoid using the dreaded "D" words around children by using indirect terms or phrases⁴. Use clear simple language which the child can understand. Identify the disease by name: e.g., cancer and not lump.
- Children 2-6 years exhibit concrete thinking and magical thinking. Avoid indirect phrases such as "*your grandpa has gone to sleep.*" They hear exactly what is said and may be terrified to ever fall asleep and never wake up.
- Children under age of 12 years may view death as a reversible or temporary event as in cartoons, anticipating their deceased loved one to wake up from sleep. Gently explain how as the disease gets worse, their loved one *dies* and the body stops to work and can no longer see, hear, think or feel².

5. Ask if they have any questions or concerns

- Children often try to protect adults closest to them from feelings of sadness⁴. They may be too scared to talk about what they fear most.
- Reassure them that it's okay to share their thoughts and feelings, however difficult or upsetting it may be.
- Taking the lead to talk to children frequently allows them to feel less isolated and provides them opportunities to work through their grief emotions
- When appropriate and desired, seek guidance from health professionals with expertise who can assist in providing accurate information and support in a way that children can understand; e.g., social worker or grief counsellor¹.

6. Be attentive to how they react

- Observe the child's reactions while you are talking, such as crying, fidgeting, or looking surprised. They may not display strong feelings upon receiving bad news, and this may cause adults to be upset ².
- Exploring why they respond that way can help you to understand the feelings behind their behaviors.
- Children under age of 2 are often comforted by the presence of familiar adults and surroundings. They respond well to being cuddled or hugging a favorite doll. Regressive behavior is common; such as being afraid to sleep alone in their own bed.

7. Be present to support their natural feelings of grief

- Unlike adults, children grieve in "chunks". They may fluctuate between feeling sad and happy from one minute to the next ².
- Reassure them that there are no wrong or bad feelings or thoughts. Acknowledge and validate their feelings, saying *"It's okay to cry or be sad."*
- Activities that are helpful for younger children to express their emotions and find comfort include: arts, crafts, storybooks, or playing.
- Support the child to find ways to keep precious memories of their deceased loved ones 'alive' in their hearts and minds;

e.g., decorating a memory box, or celebrating a birthday.

8. Address common concerns

- Holding conversations to listen and address the child's concerns can help to normalize and validate their questions, confusion and emotional reactions ².
- *"Can I catch it?"* Reassure the child that he/she cannot "catch" a non-contagious disease.
- *"Did I cause it?"* or *"Could I have cured (or fixed) it?"* Reassure the child that nothing he/she did or said that could cause or prevent their loved one's illness or death.
- *"Who will care for me?"* Child may fear being abandoned if their surviving parent/caregiver also becomes seriously ill and dies. Let them know who will care for them and where they will be cared for. Set daily routines and involve them in decisions to any changes made.

9. Check in frequently

- Children may ask the same questions over and over, or they may have new questions and concerns in attempts to make sense of the world around them ³.
- Ask and do not assume that you know what the child thinks is happening. A child may not think that grandpa is dying simply because he has a feeding tube to help him eat.



- Be prepared to repeat what you said or explain it again in a different way that makes sense for them.

Conclusion

Preparing children for what to expect when someone close to them is ill or dying is an important and essential conversation ¹. Adults supporting grieving children may not be able to

“fix” grief and shield them from the emotional pains and losses that come with living and loving; however this can pave the way to supporting healthy grieving for years to come ⁴. The best protection for children is to prepare and equip them with the information, tools and coping strategies that will help them withstand the inevitable windstorms of life.

References:

1. Lysa, T. Talking with children and youth about death. Canadian Virtual Hospice (CVH) (Nov, 2017).
2. Lysa, T. Caring for grieving children and youth. CVH (Nov, 2017).
3. McClement, S. Talking with Children and Youth about Serious Illness. CVH (Nov, 2017).
4. Warnick, A. Don't use the 'D' Word: Exploring myths about children and death. CVH (Sep, 2017).
5. Warnick, A. When to Tell the Children: Preparing Children for the Death of Someone Close to Them. CVH (Nov, 2017).

Upcoming Palliative Education Opportunities

Victoria Hospice's Psychosocial Care of the Dying and Bereaved

Running from June 5-7, we will be hosting Victoria Hospice and their Psychosocial Care of the Dying and Bereaved course. Fifty people are coming from all over to attend this three-day educational opportunity. We look forward to sharing pictures in the next newsletter.

Education Sessions by Skype

A team of experts in palliative care will be presenting a series of interdisciplinary webinars on palliative care. Health professionals from all care settings are invited to attend. A specific subject will be taught each month and repeated throughout the month to allow more people to participate. Webinars are recorded and provided on OurNH and the external website.

Month	Date & Time	Topic	Presenter
April	Thu, Apr 18, 2-3 pm	LEAP Mini—Pain	Jenny Kenny
May	Thu, May 16, 2-3 pm	Palliative Emergencies	Jenna Hemmerich
June	Thu, Jun 20, 2-3 pm	Kath Murray: 4H - Delirium (PSW)	Annie Leong

If you are interested in having your name added to our distribution list, please contact Palliative.Care.Consult.Team@northernhealth.ca

Please note: schedule subject to change