



HOW TO

TALK TO YOUR CHILD AND YOUTH ABOUT DEATH

An Overview Written by the
Supportive Care Team



Dr. Bob
**KEMP
HOSPICE**
Compassionate Palliative Care
& Bereavement Services

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This booklet is a resource of support for children. It includes a variety of information, tools, tips, and activities to guide children that may have questions regarding death, or dying.

Dr. Bob Kemp Hospice
277 Stonechurch Rd. E
Hamilton, ON L9B 1B1
childandfamily@kemphospice.org



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A LETTER TO READERS

To: The Care Giver, The Family, The Griever, or the Supporter

Can you talk about death? Comfortably, using the correct terms like died?

Most people find this topic very challenging to discuss and feel a need to soften the language. This book has been written with you in mind. It has been written so that you can talk to your children about death and the sadness they feel with their grief. This is a starting point. Please note that you can only help your children if you, yourself are supported. You need to make sure that you are taking care of yourself before you can properly help your children.

Remember, children grieve differently than adults. People in general grieve differently from each other. You might be an emotional griever and want to talk and express emotions while your child is a physical griever who displays their grief physically, like going for a run. Because they may not grieve like you, does not mean that they are not grieving. As parents/caregivers, you will marvel at the fact that children appear to be able to turn their grief “off” for a time. It’s believed that they have an inherent coping strategy that says “that’s it for now, let’s go do something else”. We call that puddle jumping. It looks like they aren’t engaged in or dealing with their grief, rest assured, they are grieving, and they have not forgotten.

Your children will have worries and might worry you. If you want them to continue to talk to you about these concerns call them something other than worry. They might stop talking so they don’t worry you. The 5 big worries for children/youth are referred to as the 5C’s; Cure, Cause, Catch, Care and Connect. We go into this further in the book but the biggest “C” worry after a parent dies is “who will take care of me”. Have a plan and do your best to communicate this plan as early as possible. Eg, “we have this plan so that you know, but we hope that we never have to use it.”.

Grief is not a destination, although we would like there to be a start and an end point. Grief is life-long. This path is different for everyone and will take detours and hit road blocks. It is not a race. In the end, we want our children to be well and happy, but the reality is that there will be sadness and suffering too. Joy and sadness can coexist. One feeling does not negate the other. It’s ok to smile and laugh even when we are grieving. Keep talking! Say your loved ones name! Remember and share your memories. Don’t be afraid of tears. You don’t need to fix this because there is nothing to fix. Your job is to love, support, be present, hold space and validate. You’ve got this!

- Dr. Bob Kemp Hospice Supportive Care Team



DEATH AND DYING

When death is brought up, what do you instantly think of? Maybe it's a specific person, a certain feeling, colour, or a place. There could be a few things we think of, or feelings we experience.

If someone approached you and asked how familiar you were with death as a child, what would your response be? What kinds of conversations were you having with your family as a child? Think about your child now, what would they say?

As a parent or caregiver, when you think about death, you may also think of a sinking feeling in your stomach, that talking about death isn't something we should do with our children. That by bringing up this conversation, it will harm them, not protect them.

In reality, these conversations are things we "must do" as parents and caregivers.

Death is a part of our living! Grief is as natural as the seasons changing. If we allow our children to talk about death to us, we can provide correct and concise information back to them to prepare them for crisis. To let them know that it's okay that they are grieving and feeling this way. By normalizing their grief, it will allow them to grieve more naturally in the future, and identify the support and resources available to them.

This booklet incorporates different activities, definitions, tips, and tricks for parents and caregivers who need some support in explaining death to their children/youth.

WHAT YOU NEED TO KNOW

- Children and youth grieve differently than adults do
- They are experiencing physical, hormonal, and developmental changes, trying to figure out who they are outside of their families, trying new things and meeting new people
- Grief is a lifelong process, it can be triggered at different times throughout a lifetime, anniversaries, milestones, celebrations, etc. In saying this, support needs to be ongoing
- The grief process can be interrupted if new struggles, deaths, or trauma occur.

PEMS MODEL

There are many different grief theories and models. PEMS is an acronym for one of these grief models.

Everyone grieves in a different way, there are no limitations, or restrictions around grief and bereavement.

Here is one way to look at it.

You are in a house with 4 different rooms. Each room gives you a different reaction and feeling when entering. In your time living at this house, you may visit all the rooms at some point, but there is always going to be one room that you go back to, and hang out in the most. This is similar to how one will go through feelings during grief.



WHAT YOUR CHILD MAY EXPERIENCE

<p><u>Physical</u></p> <ul style="list-style-type: none"> - Low energy - Appetite - Weakened immune system - Aches & pains 	<p><u>Mental</u></p> <ul style="list-style-type: none"> - Memory - Trouble concentrating - Mental fog - More stressed when dealing with regular routines or tasks
<p><u>Emotional</u></p> <ul style="list-style-type: none"> - Overwhelmed - Riding an "emotional rollercoaster" - More tearful - Feeling numb 	<p><u>Spiritual</u></p> <ul style="list-style-type: none"> - Questioning one's purpose - Challenged world views - Anger directed at a higher power - Desire for peace of mind

WHAT YOU MAY SEE

<p><u>Physical</u></p> <p>Grief is shown through doing something physical;</p> <ul style="list-style-type: none"> - Mowing the lawn - Going for a run - Building something 	<p><u>Mental</u></p> <ul style="list-style-type: none"> - Grief is shown through gaining knowledge; - Reading a book - Researching a reason - Looking for possible cures
<p><u>Emotional</u></p> <ul style="list-style-type: none"> - Grief is shown through showing feelings; - Crying - Talking about the person - Discussing what has changed 	<p><u>Spiritual</u></p> <ul style="list-style-type: none"> - Grief is shown with inner feelings like spirit and soul; - Planting a tree - Doing yoga - Praying

REMEMBER!

Everyone grieves differently, and has their own unique experiences. In families with multiple children, each child may handle their grief differently, so it is important not to compare their grief to each other.

Children are like flowers, some grow anywhere like Daisys, where some need more care like Orchids.

CHILDREN AND YOUTH RESPONDING TO DEATH

Youth: Ages 0-12	Emotions looking like sadness, anger, anxiety, shock, disbelief, denial, guilt, acceptance, and fear
	Talking a lot or not at all about the death
	Repetitive questions
	Puddle Jumping (moving rapidly from grief expressions to regular activities)
	Fear and anxiety about themselves dying
	Crying and heightened sensitivity
	Clinging and longing
	Difficulty focusing and concentrating
	Withdrawal: decreased interest in school and activities, decline in marks or achievements
	Trouble falling asleep, sleeping more, nightmares
	Acting out: bullying, non-compliance with adults, irritability, clowning around
	Physical Symptoms: headaches, tummy aches, soreness, startling easily, crying
	Changes in eating habits
	Changes in activity levels
Intense focusing and over achievement in school and activities	

Teens: Age 13-17	Emotions looking like sadness, anger, anxiety, shock, disbelief, denial, guilt, acceptance, and fear
	Talking a lot or not at all about the death
	Talking about feelings, and questions with others, but not with family
	Fear and anxiety about themselves dying
	Crying and heightened sensitivity
	Intense longing for the person who has died
	Pre occupation with death and afterlife
	Difficulty focusing or concentrating
	Intense focus and overachievement in school and activities
	Withdrawal: decreased interest in school and activities, decline in marks or achievements
	Sleeping issues: not falling asleep, sleeping more, nightmares
	Acting out: bullying, non- compliance with adults, irritability, clowning around
	Physical Symptoms: headaches, tummy ache, soreness, startling easily, crying
	Changing in eating habits
	Changing in activity levels
Avoidance and isolation: fear of leaving home, avoiding school, less time with friends	
Seeking out "normal" activities as distractions	

HOW CAN YOU SUPPORT

- Be honest and open
- Listen openly without judgement
- Avoid substitution words (ie. Use “They have died” rather than “They have gone to a better place”)
- Use age appropriate language (listed on page 16)
- Model self care: take care of yourself, seek support
- Acknowledge and validate the child/youth/teen’s grief
- Accept and respect the child/youth/teen’s feelings
- Acknowledge your own grief to teens
- Provide reassurance and validation
- Provide opportunities to talk about loved ones who have died
- Offer choices
- Provide opportunities to ask questions
- Allow youth/teens to participate in funeral, burials, memorial services, or other traditions as they seem fit
- Provide routine, with flexibility built in
- Maintain consistent rules and expectations
- Provide creative outlets
- Plan an “out” with teens for when they are in public and have a grief response
- Create rituals or spaces to honour the memory of those who have died
- Be patient
- Ask how you can help
- Share, but don’t force beliefs about death; spiritual, religious, cultural, academic
- If you do not know what to say or cannot answer a question, be honest- it is okay not to know
- Remember you are not alone. We are here to help you navigate this difficult experience.

DO'S AND DON'TS AFTER DEATH

A list provided to us through the prospective of a griever.

DO'S

- Mention my loved one who died by name
- Please do not be afraid to talk about the person who died. Don't pretend that he/she didn't exist
- Use the words "dead" "died" "death"
- Be patient. It is okay to cry and show feelings and emotions, the intention is not to make others uncomfortable.
- Call and visit. Please do not wait for me to call you
- If you see one of us sitting alone please offer to sit with us
- If you call and invite us to join you at some function and we say no, please try another time
- Thinking of you texts, cards or notes on anniversaries, birthdays etc are appreciated
- If we vent our anger toward you please forgive us
- Be happy when something good happens
- Help us laugh again
- Help us to keep the memory of our loved one alive

DON'TS

- Please don't tell us that you know how we feel
- Please don't tell us "you are the man/woman of the house now; you have to take care of your mom/dad/siblings"
- Don't avoid talking to us about our loved one because you don't want to upset us
- Don't tell us to get over it
- Please don't minimize our loss
- Don't use cliches like "we all have to die sometimes"

THE DO'S AND DON'TS WITH LANGUAGE

DO'S	DONT'S	WHY?
Your brother has cancer	Your brother is very sick	Children may fear the person who is very sick, or confuse themselves with getting sick too
Daddy died today	Daddy has gone to a better place	A child might wonder why they cannot go to that place that their father is at, if it really is a "better" place
Your sister has died	Your sister went to heaven	Using language that a child or youth may not fully understand like heaven can be challenging to comprehend. This could cause fear of being taken there, or questioning as to why they can not go there
Grandma has died	Grandma has gone to sleep forever and will not wake up	Children/ youth may experience a fear of sleeping from this, or wonder why their loved ones have not woken up
Your mother died today	We lost your mother today	Terms like lost for children/ youth symbolize that they may be found. Youth may not understand why no one is looking for their loved ones, and why they can not find them.

DEVELOPMENTAL STAGES, AND HOW THEY IMPACT GRIEF

All children will grieve differently. This grief could be affected by their age, stage of development, previous experiences with death, and the relationship with the person who died.

These developmental stages will assist you in your approach to explaining death, or supporting children/youth during their grieving process.

MILESTONES THAT YOUR YOUTH MAY HIT, THAT COULD ALTER THEIR LIFE

Erikson's Stage Theory in its Final Version.

Age	Conflict	Resolution or "Virtue"	Culmination in old age
Infancy (0-1 year)	Basic Trust vs. Mistrust If the care the infant receives is consistent, predictable and reliable, they will develop a sense of trust which will carry with them to other relationships, and they will be able to feel secure even when threatened.	Hope	Appreciation of interdependence and relatedness
Early childhood (1-3 years)	Autonomy vs. Shame Children at this stage are focused on developing a sense of personal control over physical skills and a sense of independence. Success in this stage will lead to the virtue of will.	Will	Acceptance of the cycle of life, from integration to disintegration

<p>Play age (3-6 years)</p>	<p>Initiative vs. Guilt Children assert themselves more frequently through directing play and other social interaction. These are particularly lively, rapid-developing years in a child's life.</p>	<p>Purpose</p>	<p>Humor; empathy; resilience</p>
<p>School age (6-12 years)</p>	<p>Industry vs. Inferiority children become capable of performing increasingly complex tasks. As a result, they strive to master new skills. Children who struggle to develop this sense of competence may emerge from this stage with feelings of failure and inferiority.</p>	<p>Competence</p>	<p>Humility; acceptance of the course of ones life and unfulfilled hopes</p>
<p>Adolescence (12-19)</p>	<p>Identity vs. Confusion During this stage, adolescents explore their independence and develop a sense of self.</p>	<p>Fidelity</p>	<p>Sense of complexity of life; merging of sensory, logical and aesthetic perception.</p>

0-2 YEARS OLD



Concept of Death: Death is seen as separation or abandonment.

Grief Response: They rely on sense. They do not understand that the person is gone forever, however, can sense that they are no longer there.

Signs of Distress: Difficulty toileting, sleeping, very clingy, temper tantrums, crying.

How to Support: Simple honest explanations of death with familiar examples to help their understanding. Provide physical comfort and consistent routine.

2-4 YEARS OLD



Concept of Death: Death is seen as abandonment. They believe that their loved one has gone to sleep. Believe death to be temporary, reversible and contagious.

Grief Response: Intense, brief responses to death. They present as oriented. Children will react to changes in routine and care. Asking repeated questions about the death. Anxious about their basic needs being met. - “Will mom be able to take care of me alone.”

Signs of Distress: Regression, anxiety at bedtime, fear of abandonment, seek physical contact, irritability, tantrums

How to Support: Simple, honest explanations of death with repetition. Provide children with physical comfort and consistency. Reassure that death is not contagious, and that the child will be taken care of. Allow for some regression.

4-7 YEARS OLD



Concept of Death: Death is seen as temporary and reversible

Grief Response: Child may feel responsible for the death due to magical thinking (I told them I wish they would die).

Repetitive questioning; why, how, etc? Some children may act as though nothing has happened. Feelings of confusion and distress.

Signs of Distress: Overt signs; sadness, anger, fear, etc.

Changes in eating and sleeping. Nightmares more often. Violent play, and behavioural problems. May attempt to take on the role of the person who died. Eg; a young boy would try to be like a father, if the father has died.

How to Support: Simple, honest explanations of the death.

Try to avoid euphemisms (fell asleep and is now in the sky).

Provide them with opportunities to express their feelings, and give them coping strategies. Reassure they did not cause the death if the question does get asked.

8-11 YEARS OLD



Concept of Death: May still see death as reversible, however beginning to see it as final. May think that death is punishment for bad behaviours or thoughts.

Grief Response: Feeling angry or responsible, want to know details and specific questions. Concerned if others are reacting the same (like other kids). This age has more ability to mourn and understand death.

Signs of Distress: Overt signs, physical complaints, overactive to avoid thinking of death, feel ashamed and different from other children, problems in school, withdrawal from friends, acting out, concerns with body, role confusion.

How to Support: Open, honest explanation of death, answer questions, provide opportunity to express range of feelings, coping skills, physical outlets, reassure that they are not responsible.

12-18 YEARS OLD



Concept of Death: Death is inevitable, universal and irreversible, abstract thinking, can conceptualize death.

Grief Response: Depression, denial, repression, more talkative to others outside of family, embarrassment, place peer needs ahead, traditional mourning, not wanting people to know.

Signs of Distress: Depression, anger, non compliance, difficulty concentrating, withdrawal, engaging in high risk behaviours

How to Support: Communicate using direct open dialogue about death. Encourage verbalization and listen, however, do not force communication. Set consistent limits balanced with freedom and choices. Grief is life long with no end point. Continue to support and honour this process through milestones, traditions, and and occasions.

BILL OF RIGHTS OF GRIEVING TEENS CREATED BY THE DOUGY CENTRE LOCATED IN PORTLAND OREGON.

- 1.To know the truth about the death, the deceased, and the circumstances
- 2.To have questions answered honestly
- 3.To be heard with dignity and respect
- 4.To be silent and not tell you their grief emotions and thoughts
- 5.To not agree with your perceptions and conclusions
- 6.To see the person who died and place of death
- 7.To grieve any way they want to without hurting self or others
- 8.To feel all the feelings and think all the thoughts of their own unique grief
- 9.To not have to follow the “stages of grief”
- 10.To grieve in ones own unique way without censorship
- 11.To be angry at death, at the person who died, at God, at self, and at others
- 12.To have their own theological and philosophical beliefs about life and death
- 13.To no be taken advantage of in this vulnerable mourning condition and circumstances
- 14.To have guilt about how they could have intervened to stop the death

ACTIVITIES FOR GRIEVING CHILDREN/ YOUTH/TEENS

Memory Mailboxes: Use any type of box (Kleenex box, cardboard box, etc) if there is not a slit already in it, cut a small letter sized slit in the top. Write letters, share memories, pictures, anything that they wish to send to their person.

Journal: If they are hesitant to share things with others, encourage them to write down their own thoughts in a book. Have them pick out their own journal, decorate it if they wish.

Finish the sentence: Write out sentence starters and have them finish them off. It is common for them to have a sense of uncomfortableness towards starting the conversation.

Memorials: Posting something on social media, creating a memorial where they had died etc.

Worry Doll: Create a pipe cleaner stick figure, and begin wrapping it up with yarn until you cover it completely. Give all these worries to your worry doll and hide it under your pillow at night.

RESOURCES FOR GRIEVING CHILDREN (3-12 YEARS)

Books are great resources for children to use when processing grief. Here are a few suggestions:

- When Dinosaurs Die By: *Laurie Kransy Brown*
- IDA Always By: *Caron Levis*
- Always and Forever By: *Alan Durant*
- I Was So Mad By: *Mercer Mayer*
- My Many Coloured Days By: *Dr. Seuss*
- The Colour Monster By: *Anna Llenas*
- The Empty Place By: *Roberta Temes*
- Lifetimes By: *Bryan Mellonie*
- Samantha Jane's Missing Smile By: *Donna B. Pincus and Julie B. Kaplow*
- The Invisible String By: *Patrice Karst*

RESOURCES FOR GRIEVING TEENS (12-18 YEARS)

Books are great resources for teens to use when processing grief. Here are a few suggestions:

- Lights For The Path By: *Madeleine Davies*
- Part of me Died, Too By: *Virginia Lynn Fry and Katherine Paterson*
- What is Goodbye? By: *Nikki Grimes*
- A Grief Observed By: *C.S. Lewis*
- A Monster Calls By: *Patrick Ness*
- Straight Talk About Death For Teenagers: How To Cope With Losing Someone You Love By: *Earl A. Grollman*
- You Are Not Alone: Teens Talk About Life After The Loss of a Parent By: *Lynne B. Hughes*
- Healing Your Grieving Heart For Teens By: *Alan D. Wolfelt*
- The Problem of Pain By: *C.S. Lewis*
- When a Friend Dies: A Book For Teens About Grieving and Healing By: *Marilyn E Gootman*

WHAT THE DR. BOB KEMP HOSPICE OFFERS

All items listed below are delivered by trained staff or volunteers at no cost.

Adult (18+)

- Adult 1-1 Counselling
- Peer Support Matches
- Grief Text and Online Chat
- Adult Open or Closed Support Groups

Child/ Youth (5-17)

- Child/ Youth 1-1 Counselling
- Grief Text and Online Chat
- Child/ Youth Open or Closed Support Groups
- Monthly Event Nights
- Camp Keaton

Closed Group

- 6-8 Week Seasonal Program
- Registration is Required

Open Group

- No Commitment is Required
- Drop in as you Need

To sign up, or for more information please visit us at kemphospice.org



NOTES: