northstar
Care Community

HELPING GRIEVING CHILDREN AND TEENS:

Educational Resouces for Caring Adults

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Talking with Children, Teens, and Caregivers about Illness and Dying

Children and Teens have an innate ability to determine their needs – this holds true for children who state a desire to remain with a dying loved one and for those who opt to spend time in the Hideaway or their 'safe place'.

In order to determine their needs, children must be given the chance to receive information about a situation. Some important information that can assist children in determining their needs include:

- the **emotional** tone of adults, specifically related to crying and sadness.
  - (it is important for caregivers to **assure** children that, even though they are sad, they will be ok and able to take care of their child)
- the physical state of their loved one
  - physical **symptoms** related to how the patient appears/what the child might **see.**
- permission and modeling to interact/**touch** the loved one.
- permission to do what is **comfortable**/manageable, like drawing a picture for their loved one in the place of remaining in the presence of their loved one.

BEFORE DEATH

- Do say '**illness**', '**disease**', '**virus**', etc. in the place of 'sick'. Describing illness as 'sick' can result in children thinking that they or others will die as a result of simply having a cold, allergies, etc.
- Do explain dying from a disease in terms of the disease becoming strong, like "the disease has become so strong that their body isn't working right anymore. Nurses and doctors tried everything they could to stop the disease, but the treatments didn't work".
- Do explain dying from old age in terms of body parts wearing out, like a car.
- Do explain dying from a faulty organ in terms of what has caused the organ not to work properly. Explain how important the organ is to the rest of the body continuing to work.

CHILDREN AND TEENS

It is beneficial for a child to have the **choice** to interact with their loved one.

- In the case that a caregiver is questioning the usefulness of their child seeing their loved one, it is important to know that children gain understanding through **concrete** experience (like seeing a loved one who is ill or has died).
- Caregivers should know that children possess the need to say goodbye, just like adults.
- Offer the presence of a trusted other. Because children are most comforted by people familiar, caregivers can offer **support** to the child when interacting with their loved one.
- If a child desires, yet is reluctant to touch, offer to **facilitate** the touch.
- To assist the child in feeling a sense of control and helpfulness, suggest that they too can help with age-appropriate tasks, like getting ice chips or fluffing pillows.
- In the case that a child must leave their loved one, reassure them that their loved one will be cared for and ask if the child would like to leave anything with the loved one in the child's place, like a picture or favorite object.
- **Hearing is the last sense to go!** – be sure to let the child know that 'nurses and doctors tell us that hearing is the sense we have the longest' and that they can share some thoughts with their loved one (in-person or virtually).

ADDITIONAL CONSIDERATIONS FOR TEENS

A significant illness or death during the teen years is tough because developmentally, teens are working to be more independent from their caregivers. However, serious illness and death typically create the desire for family members to rely more on one another. Some teens turn to their family members for support while others turn to friends or mentors. It is important for teens to identify at least one person in whom they can confide while making sense of death and loss.

A teenager being emotionally reserved and aloof does not mean that they are not distressed by the illness/death of their loved one. The best thing caregivers can do is model open sharing with their teen. This lets the teen know that the caregiver is safe to talk with about the illness/death.

Developmental Chart

Understanding the Grief of Children and Teens

Age 0-2

Developmental Characteristics

- Sees caregiver as source of good feelings and interactions
- Explores environment around him/her
- Self-centered focus
- Can show and feel emotions, i.e. anger and love
- Needs consistency
- Completely dependant on caregiver

Concept of Death

- May see death as reversible
- Grief response is only to the death of a significant person in child's life
- Searches for caregiver
- Reads primary caregiver's distress and reacts to the distress
- May regress in behavior

What Helps

- Needs support, comfort, and love from significant others
- Maintain schedule of daily activities
- Tell a simple story of the death and that their loved one will not return; elaborate when he/she is older.

Age 2-5

Developmental Characteristics

- Thinking is concrete, child takes everything literally
- Magical thinking; child spends a lot of time thinking of make-believe concepts
- Cause and effect are often confused; guilt and punishment often misperceived
- Separation anxiety
- Completely dependant on caregiver
- Time and space concepts are limited; doesn't always have a frame of reference for what one week means vs. one month
- Self-centered focus

Concept and Response to Death

- Grieving is often non-verbal
- Death is seen as reversible because people who leave come back
- Comfortable interacting with someone who just died
- Have guilty feelings (however illogical) of causing death
- Behavior regressions, clinging, aggressive
- May identify with patient through somatic complaints
- Worries about who will take care of him/her
- Worries that everything will change; searches for normalcy

What Helps

- Encourage understanding of causes for illness and death in simple language
- Reduce self-blame by clarifying any misconceptions
- Acknowledge child's (and your own) sad, lonely, and angry feelings
- Encourage play and verbalization activities
- Encourage that life will continue and that a steady source of care-giving will be there for the child
- Include child in ceremonies, after describing what might be seen and experienced
- Assure the child that his/her health and other significant individuals are healthy
- Maintain schedule and routine.

Developmental Chart

Understanding the Grief of Children and Teens

Age 5-9

Developmental Characteristics	• Begins to understand cause and effect • Understands consequences of people's actions	• Literal and concrete • Fantasy life is lessening • Can try to control feelings • Tries to make sense of the world
Concept of Death	• Begins to understand that death is irreversible • May see death as a punishment • Interested in the biological aspects of death • May feel they caused the death, which may produce guilt, anger, rejection, detachment, or excessive care-giving	• Feelings may surface through behaviors such as concentration difficulties, complains of physical problems, grades dropping at school, headaches, and stomachaches
What Helps	• Include child in the funeral ceremonies, if they choose • Give permission to express feelings and provide opportunities • Reduce guilt by giving factual information about illness and death	• Maintain a schedule of daily care and activities • Provide opportunities to remember their loved one • Adults expressing grief is helpful model.

Age 10-12

Developmental Characteristics	• Capable of responsibility • Can verbalize feelings • Develops own way to explain life and death	• Desires to be involved • Desires a "normal" family
Concept of Death	• Finality: death is the end of physical life and existence • May think they are immortal	• Egocentric: how will the death affect me? • Curiosity about the meaning of life
What Helps	• Remind the child that their primary job is to be a kid and be cared for by adults • Find ways to say goodbye, express grief, and to remember their loved one	• Find simple patient care-taking tasks for child such as reading to the patient • Introduce them to others who have experienced a similar loss.

Developmental Chart

Understanding the Grief of Children and Teens

Age 13-18

Developmental Characteristics	• Developing social skills; occasionally rejects parental control and tests limits • Relationships and peer groups are of vial importance; cliques develop	• Romantic relationships establishing • Begins to separate from family while needing adults as safety net • Wants to be treated like an adult
Concept of Death	• Understands future and what the loss will mean • Attempts to make sense of death • May have guilt due to greater connection to peers than family	• May take on care-giving and other responsibilities • Intense feelings of loss, depression, denial, and exhaustion
What Helps	• Include in funeral ceremonies, if they choose • Give permission to express feelings and provide opportunities for expression	• Encourage relationships with other peers and adults • Help teen to dream of goals and wishes for the future

Helping Children & Teens Deal With Death

DO:

- Share your own feelings.
  - Encourage tears.
  - Respond to the child's feelings.
  - Allow time for mourning. (Can be months)
- Recognize that there are many emotions in the grief process and accept that children go through a multitude of emotions too.
- Be honest at all times.
  - When explaining, identify with something familiar to the child.
  - Answer the child's questions candidly and rationally.
- Allow the child to become involved.
  - Look for the child's needs and fulfill these needs if possible.
  - Allow the child to help fulfill the needs of the surrounding adults.
- Discuss death with your children.
  - Explain in advance about funeral rituals.
  - Discuss the funeral service. (Mortuary, church, graveside)
  - Listen to what your child has to say.

DON'T:

- Attempt to hide your feelings
- Fail to recognize behavior problems may be transferred emotions.
- Tell half-truths and fairy tails.
- Provide a theological lecture (preach).
- Imply a temporary situation. (He has gone away) (She is sleeping)
- Blame God (It's God's will)
- Leave explanations incomplete. (He was sick. So am I, will I die?)

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National Certified Counselor

Common Feelings, Thoughts, & Behaviors of the Grieving Child

Child retells events of the deceased's death and funeral.

Child dreams of the deceased.

Child feels the deceased is with them in some way.

Child rejects old friends and seeks new friends who have experienced a similar loss.

Child wants to call home during the school day.

Child can't concentrate on homework or classwork.

Child bursts into tears in the middle of class.

Child seeks medical information on death of deceased.

Child worries excessively about their own health.

Child sometimes appears to be unfeeling about loss.

Child becomes "class clown" to get attention.

Child is overly concerned with caretaking needs.

Life & Loss (2000)

How Caring Adults Can Help Children & Teens With Their Grief

The first thing to communicate to a child is "You are not alone: I am with you."

Share feelings with children. They want and need information and participation in the grief process. (Often adults wish to protect their children from reality seeing it as a time of innocence.)

Let children know that feelings take precedence — stop cooking, reading the paper, etc.

Make sure children get the clear message that the illness was not their fault. It was not because they were bad in any way or because they were unlovable. Neither was there anything they could have done or still do to alter the situation.

Do not tell the child "Don't worry" or "Don't be sad" etc. As with adult grief, they are unable to control their responses. Also avoid messages that tell the child what they should or should not be feeling. Do not criticize or seem shocked by statements and feelings.

Encourage the child to accept strong feelings explaining that recovery to creative healthy living involves pain. Unfortunately there is no short cut.

Do not deny your pain. It is all right to cry in front of your child.

Try to avoid the statements "falling asleep and will not wake up."

Caregiver-teacher co-operation should be sought. Teachers underestimate the time that a child will be disorganized

Do not worry about 'regression.' Allow it until equilibrium and energies are renewed. The child usually emerges stronger and more competent.

Respond patiently to their concerns and questions. Children can sometimes be repetitive as they search for answers.

To increase confidence, encourage the child in all their abilities.

Adapted from: American Hospice Foundation. Grief At School: A Guide for Teachers and Counselors.

Reactions	Needs
Anxiety	Security
Guilt	Reassurance
Terror/ Fearfulness	Adult protection, acknowledgement, patience, simplification of tasks
Constantly worried that something else will happen (hypervigilance)	Structure, consistency, facts, information, simplification of tasks
Helplessness	Physical nurturing, simplification of tasks and expectations
Chaotic or out of control feelings and emotions	Calm, peaceful environment
Fatigue	Sleep, predictability, calmness
Repetitive telling of the story or reenactment in play of incident	Someone to listen
Fear of being alone (difficulty leaving parent or letting parent leave)	Safety and conviction that self and others will be safe
Confusion, forgetfulness, inability to concentrate	Simplification of tasks, repetition, structure, patience. Teachers and counselors may need to be made aware of this inability to concentrate.
Worry about something else happening to him/herself	Reassurance, sense of safety

http://www.tlcinst.org/PTRCneeds.html

Practical Ideas For Caring Adults to Help Grieving Children

Resist the urge to encourage the child to stop crying. Instead hold them gently and let them cry as long and as hard as they want to.

Participate in the child's favorite activity with them, whether it is sports, art, or whatever.

Do something appropriately childlike with the grieving child today. Take them to the park or play tag with them.

Tell them "I love you" or "you are important to me"

Surprise the child with a special gift or activity today.

Rent a silly movie and watch it with the child.

Do a memory project together like a memory box, collage, tree ornament, or stone decorating.

Adopted from Healing the Grieving Child's Heart: 100 Practical Ideas for Families, Friends and Caregivers 2000 by © Alan Wolfelt, PhD

Signs When Grief In Children & Teens May Require Additional Support

If a child pretends absolutely nothing has happened.

If schoolwork takes a dramatic decline or the child develops a phobic fear of school.

If news of a death or other significant loss was kept from the child for a long time or if the child was told lies about the death.

If a child threatens suicide.

If a child panics frequently.

If a child physically assaults others or is cruel to animals.

If a child had a difficult relationship with the deceased or behaves poorly with the family members.

If the child becomes involved with drugs or alcohol.

If the child begins committing serious socially delinquent acts.

If the child is unwilling or unable to socialize with other children.

Contact your hospice Grief Support Manager for support and resources.

Suggested Reading for Children & Teens on Death and Dying

Children

Brown, L. & Brown, M. (1996). When Dinosaurs Die. Ages 3+

Buscaglia, L. (1982). The Fall of Freddie the Leaf: A Story of Life for All Ages. Ages 4+

Dennison, Amy, Allie and David. (2003). After You Lose Someone You Love. Ages 8+

DK (2021). Lost in the Clouds: A gentle story to help children understand death and grief. Ages 3+

Dorn, A. (2022). When Someone Dies: A Children's Mindful How-To Guide on Grief and Loss. Ages 4+

Durant, A. and Gliori, D. (2004). Always and Forever. Ages 4+

Hemery, K. M. (1998). The Brightest Star. Ages 6+

Kaplow, J. (2007). Samantha Jane's Missing Smile: A Story About Coping with the Loss of a Parent. Ages 4+

Karst, P. (2018). The Invisible String. Ages 3+

Levis, C. (2016). Ida, Always. Ages 4+

Mellonie, B. and Ingpen, R. (1983). Lifetimes: The Beautiful Way to Explain Death to Children. Ages 3+

Mills, J. (2003). Gentle Willow: A Story for Children about Dying. Ages 4+

Mundy, M. (1998). Sad Isn't Bad: A Good Grief Guidebook for Kids Dealing with Loss. Ages 8+

Parr, T. (2015). The Goodbye Book. Ages 2+

Rawson Hill, A. (2020). You'll Find Me. Ages 4+

Ringtved, G. (2016). Cry, Heart, But Never Break. Ages 4+

Roland, J. (2017). The Memory Box: A Book About Grief. Ages 4+

Schwiebert, P. (2005). Tear Soup: A Recipe for Healing After Loss. Ages 6+

Thomas, P. (2001). I Miss You: A First Look at Death. Ages 3+

Viorst, J. (1971). The Tenth Good Thing About Barney. Ages 6+

Suggested Reading for Children & Teens on Death and Dying

Pre-Teens/Teens

Eldon, A. (2002). Angel Catcher for Kids: A Journal to Help You Remember the Person Who has Died.

Fitzgerald, H. (2000). The Grieving Teen: A Guide for Teenagers and Their Friends.

Meyers, E. (2006). Teens, Loss, and Grief: The Ultimate Teen Guide.

Popowitz, C. (2017). Grief Recovery for Teens: Letting Go of Painful Emotions with Body-Based Practices.

Samuel-Traisman, E. (1992). Fire In My Heart, Ice In My Veins: A Journal for Teenagers Experiencing Loss.

Wolfelt, A. (2001). Healing Your Grieving Heart: For Teen: 100 Practical Ideas.

Also see: The Healing Your Grieving Heart Journal for Teens (2002).

Alzheimer's Disease

Acheson, A. (2009). Grandpa's Music. A Story about Alzheimer's.

Altman, L. (2002). Singing with Momma Lou.

Scacco, L. (2006). Always My Grandpa: A Story for Children about Alzheimer's Disease.

Schnurbush, B. (2007). Striped Shirts and Flowered Pants: A Story about Alzheimer's Disease for Young Children.

Shriver, M. (2004). What's Happening to Grandpa?

Stark-Mcginnis, S. (2020). The Space Between Lost and Found.

Tauber Prior, B. & Drummond, M. (2017). Grandma and Me: A Kid's Guide for Alzheimer's and Dementia

Van den Abele, V. (2007). Still My Grandma.

Cancer

Ganz, P. (1996). Life Isn't Always A Day At The Beach.

McVicker, E. (2018). Butterfly Kisses and Wishes on Wings-When someone you love has cancer...a hopeful helpful book for kids

Olsher, S. (2019) Cancer Party!: Explain Cancer, Chemo, and Radiation to Kids in a Totally Non Scary Way

Olsher, S. (2019). What Happens When Someone I Love Has Cancer?

Sliwerski, J. (2017). Cancer Hates Kisses

Note: Many of these titles can be found on YouTube for narrated version.