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November 2005

from

The Duke Patient/Family Resource Center

The Duke Patient/Family Resource Center is:

- A lending library offering books, audio and video tapes, magazines and free brochures dealing with cancer and certain blood disorders and with issues of coping, survivorship, caregiving, and grieving
- Open 8:30 to 5:00 every day the Morris Clinics are open
- Located in the White Zone, first floor, of the Morris Cancer Clinic, Room 15123.
- Our phone number is 919-684-6955. Our email address is FamilyLibrary@mc.duke.edu



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Contents: Grief in Children

Some Generalizations

- Children aren't that different
- The peer factor
- The orphan factor
- A sibling's death

Primary Emotional Responses

- Denial and Blocking
- Anger
- Fear
- Guilt
- Sadness/Depression
- Family dynamics

Some Books in Our Collection



"Grieving is the mark of having been close to someone. The only way to avoid grieving is to avoid having loved." -Joanne Lynn, *Handbook for Mortals*

Some Generalizations

Children aren't that different. Grief in children is grief in all of us really. While there are some distinctions to bear in mind where children and teens are concerned, the experiences of grieving they undergo at the loss of a loved one are easily recognized in the

experiences that adults confess to in the same circumstances. Adults have some advantage in being able to more readily identify and articulate their feelings, and they do have a better grasp of the permanence of death. But they, like children, manifest sadness/depression, guilt, anger, fear, and denial at the loss of an important bond. And in most cases they wear their mourning longer than a child or an adolescent.

We will concentrate on the young set, however, to continue themes not completed in our September newsletter on telling children and helping them cope with the serious illness of a family member. There will be those families in which the seriously ill family member dies. How do the survivors cope with this and especially, how do the adult survivors help the child survivors to cope?

Certain principles are repeated in all the advice books:

- Be honest and direct with children. If you use euphemisms, like "Daddy has gone away on a long trip," younger children will readily misinterpret the situation as one that is less than final. (Or experience rejection if Daddy stays away too long on his "trip.") Even trying to convey a religious interpretation can get you in trouble if it contains too much evasion. Children have been known to announce that they plan to "die" at Christmas, so they can spend the holiday in heaven with Mom.
- Lots of hugging and touching and letting children cling when they feel the need are an essential part of the healing process. If it means taking more time off from work, so be it. If it means letting the children share your bed for a while, that may be a good solution. Warm, huggy, relatives or friends can be wonderful to have around in the first few weeks - for oneself as well as the children.
- Children, especially younger children, will need help in getting a grasp of the feelings they need to work through. Guide children toward the use of symbolic materials - little ceremonies and rituals, clays to mold, paintings to paint, punching bags to punch, and letters that can be mailed off to heaven. These media help children to tease apart and deal with the painful confusions they are feeling, and they help you to spot matters you can helpfully clear up. "No, honey, Daddy didn't die because you hit Debbie and made her cry."



- Be open to moments when a child decides to speak his mind, even if it seems like a weird occasion, e.g. in the line at airport security or while washing the dog.
- It is best if children attend the funeral, though a child should not be forced. If there is obvious fear or reluctance, sometimes a "dress rehearsal" beforehand - as recommended for hospital visits too - can help the child overcome his or her trepidations. Visits to the grave of the deceased are also helpful in getting children to come to terms.
- For the very young, nature walks can be a good vehicle for gentle discussions of death. You will encounter dead leaves, insects, etc. as examples.
- Find and read to the child age-appropriate books dealing with death and the changes children go through with the loss of a family member. A list of the our holdings here at the Patient/Family Resource Center appears at the end.
- Be patient with the child who asks the same uncomprehending question over and over.
- Drop the stiff-upper-lip act, at least some of the time. Children need to see that they are not alone in their anguish.

The peer factor: An important way in which children are different from adults:

"I don't like talking about my father's death too much because I don't want to feel pitied. I don't want my friends to say, "Oh, look at poor Peggy, her father died. We all have to protect her." I worry that they'll

think I'm helpless, and I'm not helpless." Peggy Laird (8 at time of father's death), *How It Feels When a Parent Dies*, by Jill Krementz.

In addition to needing more help articulating feelings, children and teens are more intensely vulnerable to peer responses during their period of loss and mourning. Many kids report experiencing embarrassment, shame, and a sense of diminishment, when they realized their peers knew and were feeling pity for them. And peers aren't always adroit at expressing sympathy. It can help enormously if the death news is conveyed to the child's main teachers before he or she returns to school and these teachers asked to prime the classroom. Sometimes it can be arranged that a joint card or poster from all of the child's classmates be handed to her or him upon return. This relieves the other children of having to decide how to handle the matter (with many deciding to avoid the stricken playmate), and it relieves the child, in turn, of numerous awkward individual encounters.

The emotional salience of peers in the child and teen's life can have its upside if the child meets or is put in touch with another child of the same age or slightly older who has endured the loss of a key family member as well. Often a important bond springs up between the two.

"When I do need to talk to someone, I usually talk to Ingrid. She's sort of like a big sister to me. She's sixteen and her father died two years ago, so she's gone through the same thing. When my father first died, she came over every day and I told her everything I was feeling. It made me feel better to get it out instead of keeping it inside. It's better sometimes to talk to her instead of my mother because I don't like to make my mother more upset than she is already."

Laura Marshall, age 12, in *How It Feels When a Parent Dies*.

One way to arrange a get-together between your child and a similarly affected peer is to contact a local bereavement center or grief support personnel in the child's school or in one's faith community. Those in the Triangle area should check with the Unicorn Bereavement Center in Hillsborough which specifically has programs for children experiencing grief. Their website is http://dukehealth1.org/dhcc/unicorn_center.asp

The orphan factor. Even after the tough period of mourning is over, an individual who loses a parent early in life will have to face a form of orphanhood through his or her remaining youth, as distinct from his happy-go-lucky peers who have Dads to show up on Dad's Day at school, and Mothers to give cards to on Mother's Day. This can cause an ache years after the memories of the

deceased have faded. One man who lost his father at age three writes:

"There is a hole there when I think of my father. It is marked by absence, not just for my own father, but for the role of father as well. I don't know what 'father' means." -cited in Maxine Harris, *The Loss That Is Forever*

The surviving parent, step-parent, or foster parent must remain sensitive to this, even while respecting the often very private feelings the child may have on the issue. In the years immediately after the death, sometimes a child will agree to shuffle activities and even holidays - drop Little League and take up swimming, do Christmas in a different city, etc. - so as to avoid needlessly stirring up futile yearnings.

The longer-range consequences of losing a parent early in life take us beyond this newsletter. Suffice it to say that they are not trivial, as Maxine Harris has demonstrated in the book just quoted. Adults remembering the trauma of their parent's death will often recount a legacy of insecurity and fear of re-traumatization in any close relationship. At the same time, the things remembered as most healing, paradoxically, were strong bonds - with a surviving family member, with mentors, or with peers who, from having been orphaned themselves, were able to convincingly understand the situation.

The difficult situation of a sibling's death. Here is a tough situation unique to the younger set. In a family where one child is fatally ill, the well child has suffered not just the anxiety about her sibling's chances, but usually as well a deficit in parental attention compared to the sick one. This deficit, or perceived deficit, can give rise to guilty hopes of having it all end and be done with. With the sick child's death, the well child may find that his grieving parents are still emotionally unavailable and that nothing has improved. The deficit continues, now compounded by loss and by guilt.

Obviously, it's best if this issue can be anticipated and headed off before a knot of confused feelings tightens. Whenever possible, quality time should be set aside for the well child or children - time that involves getting out of the house for a while and away from the atmosphere of pain and distress. Make clear to your well children that you yourself are longing to have more time with them and regret when the situation sometimes makes that difficult. When time and privacy allow, probe feelings gently to see whether a well child is harboring the kind of apprehensions that a parent can help to dispel. Symbolic media and play can come in handy in this regard. If indeed a well child is fearful and ashamed about her death wishes for her sibling, explain to her that bad thoughts have

had nothing to do with her sibling's death and that even the adults sometimes had the same bad thoughts.

Primary Emotional Responses and How to Deal with Them



Denial and blocking

Denial is more common when death is sudden and unexpected. When cancer is the cause, usually all family members have had longer to prepare. But children who have never experienced a close death will be relatively clueless as to what they are preparing for. As a result, unrealistic fantasies may crop up shortly after the death - the notion, for instance, that doctors have stolen away the missing parent, or that heaven is a place we'll all be able to visit for Christmas, or that the person they saw in that coffin was not really the deceased. In general, frequent talks with the confused child, talks that may include funeral planning, discussions of how life will go on without the deceased, etc. and a readiness to drop everything and listen if the child suddenly decides to open up, will gradually pull the child past the denial phase. Only if a child stubbornly refuses to listen to talk about the deceased, leaving the room or abruptly changing the subject each time the the name of the deceased comes up, should one begin to grow concerned and seek professional advice.



Anger

Many people are surprised to discover that anger, anger to the point of rage, is a common component of mourning. They are surprised to see it in their children, and surprised to experience it themselves. "You get mad," one grieving husband told me, "You get mad at everybody!" Yet this kind of response is reported around the world and even emphasized in the grief rituals of some cultures. Thus, it is very possible for surviving family members to find on their hands a petulant, door-slamming child, to whom nothing is enjoyable and everything is "aggrieving." He or she may develop a strong aversion to another family member, the whiny kid sister or awkward Uncle Mort. The school friends he valued so highly a month ago are now all pronounced "stupid." She doesn't want to participate with other family members in the "dumb" things they are doing to make themselves feel better.

This incoherent anger response contains a knot of common gut reactions to the sheer pain of loss. One is the sense that it is unfair and somebody's fault. The doctors gave the wrong medicine, the deceased brought it on himself by not taking the "right" medicine, God failed us, caregivers messed up. Rage at the deceased simply for abandoning one is common, especially in older children. Another component is the loneliness of noticing - sometimes mistakenly - that the people around one do not seem to share one's pain, at least not to the same degree or in the same way, and thus "nobody understands." A young woman who lost her kid sister when she was 15 writes,

"I can remember the first Christmas after her death. I was so angry. I can remember sitting at the dinner table and feeling I was the only one recognizing that she wasn't there. I'm sure everybody else was in as much pain as I was, but no one said anything.... You know, grief is so selfish." -cited in Elizabeth Richter, *Losing Someone You Love*

Similarly, one of the child's "stupid" school friends may have made an insensitive comment and the others giggled. The whiny kid

sister and awkward Uncle Mort are taking up all the attention of the surviving parent, which the enraged child desperately wants.

Finally, in angry outbursts there is the implicit plea, "Fix it! It hurts! Mommy, Daddy, fix it!"

Symbolic media (the clay and drawing materials mentioned earlier) and displacement activities can prove very useful in helping your child to channel his or her rage. Have the child draw all the things that make him feel angry. Have her model some of these in clay, then hurl them against the wall. Install a punching bag toy and encourage its active use. Take the child out jogging. In quieter moments, share with your child, philosophically, some of your own recent angers (Uncle Mort might be getting to you, too), and see if this doesn't help her better identify her own. If the mood seems right, make fun of the things that are bothering you or your child. A good conversation of this sort can spiral into goofiness and laughter, dispelling a lot of that aggrieved energy.



Fear

"The death of a loved one tends to shatter the child's perception that the world is safe and secure. [Children] see and experience the explosion of emotions following the death. They see a surviving parent crying and emotionally unavailable to them for a while. Things happen around them that they don't understand." -Helen Fitzgerald, *The Grieving Child*

The fear can take many forms. Fear that the other parent (or another sibling) will die next. Fear of dying oneself. Fear of abandonment, of having no one. Fear of the dark. Of death. Of ghosts. Regression, whimpering, clinging, bad dreams, night time compulsive rituals, are all signs that fear is ascendant.

Usually, it passes. In the meantime, try to keep the child's routine intact and preserve the child's room as a safe refuge. (No invasion from visiting relatives, unless the child himself desires it.) Structure in more time with the child, questioning and talking,

keeping the child updated on the things going on around her. If time is scarce, consider taking the child on errands with you, or even to work on light days. Frequent touching and permissiveness toward clinging are important. Some indulgence in response to what may seem to be babyish needs may actually help the fear problem to resolve more rapidly. When recurrent nightmares are the problem, it sometimes helps to have the child draw the dream story, but then draw in an acceptable ending. Helen Fitzgerald, the therapist quoted above, worked with a 6 year old whose mother was dying of cancer. The girl had repeated nightmares about lots of black snakes. After she had produced a picture of them, she decided that the correct ending was to "X them out."

"Which she did. She X'd them until you couldn't see any of them, and she continued to X them until the paper tore into shreds and she threw the drawing in the trash. She received immediate relief from this distressing dream."



Guilt

Adults may think they have cornered the market on this particular response, having had all those many years in which to indulge in hurtful behavior toward the deceased, but children are absolute geniuses at inventing guilt where there is none, or virtually none. Natural childhood egocentrism, which makes the child to connect everything to himself, plays a big role here. Every "bad" thing the child may have done, leading up to the illness or the death, becomes associated in her or his mind with the misfortune. The time she let the cat out and it got lost, the time he wet his bed, all the times he made Debbie cry, the time she got peeved at the deceased and said something spiteful.

A guilt-ridden child will be more vulnerable to prolonged depression, may develop compulsive "goodness," and may be overly eager to find blameworthiness in others.

Once again, play and symbolic media can be put to use to elicit the guilty thoughts that the child has been ashamed to reveal. Drawing pictures of scenes that the child, if she had it to do over again, would do differently, can draw out the problem idea. Sharing the problem idea with others, especially with other children who have comparable ideas, alleviates a lot of pent up guilt. Disconnect the associations that require disconnection, e.g. "Losing the cat absolutely had nothing to do with Mom's cancer." But those felt guilts that were organic to the relationship with the deceased, such as a remembered angry outburst, or a lie, may be better resolved by having children write a letter or speak into a tape recorder, addressing the deceased and saying they are sorry. These sessions of winking out guilty thoughts and making symbolic amends can be best brought to a conclusion by having children remember all of the "good" things they've done, things that made their missing relative proud or happy.



Sadness/depression

It is a very tough call deciding when "normal" mourning turns into "depression." Contemporary thought now leans toward the argument that even realistic grieving is a form of depression and takes its toll on the brain and the immune system in the same way that classic depression does [Peter Kramer, *Against Depression*]. So rather than suppose there is a normal form of grief and sadness, which is healthy; and an abnormal form which is labeled "depression" and is unhealthy, it might be best to simply focus upon duration and depth. With an important loss, the toll on our brains and immune systems is, for a while at least, simply unavoidable. It is when mourning becomes protracted in its deeper form that one should begin to think of ways to intervene.

For adults suffering the loss of an important bond, the heavy phase of mourning endures for 2 to 6 weeks, while a more intermittent, less focused ache of loss continues for 2-4 years. Someone said, "Mourning never ends; only as time goes by, it erupts less frequently." Often somewhere in the 2 year zone, there will be a

notable resurgence of interest in the outside world and a sense of relinquishing the pain. However, far earlier than two years, the average adult will have returned to work and a decent semblance of ordinary functioning. He or she is coping, even though dragging.

Deep grief in children has a more intermittent appearance right from the start. In very young children, Kathleen McCue describes the reaction as often, "Happy, happy, happy, devastated!" [McCue, *How to Help Children through a Parent's Serious Illness*] This may make it harder to tell what is really going on with a child. But roughly speaking, the duration issue should parallel that of adults. School performance is often a good barometer. One can expect disruption and falling grades in the first couple of months. The child may have somatic effects, and plead illness to stay home. Appetite for life as well as for food may go off for a while. There may be regression to thumb-sucking and other forms of childish behavior. But then slowly things should start returning to normal, even though episodes of withdrawal and sadness will continue to occur.

If a child persists beyond about 6 weeks in withdrawal, sadness, lack of joy or interest, certainly if a child hints at suicide, this is a time to seek professional help. One of the things recommended by the professionals is for other family members to share reminiscences with the child, including those that depict the departed as less than totally saintly. Conflicts the child may be hiding in regard to the deceased can more easily come to light this way. In addition, a child may be encouraged to collect keepsakes, sort old photographs, visit the gravesite, or re-read letters from the deceased (especially those that pertain to the child) in order that he or she feel that there are positive ways of relating to a person even after that person's death.

Watch for family dynamics. When a group of related people all face the same distressful event, they seldom face it similarly, at least not on the surface. This is only partly because individuals, even members of the same family, are diverse. It is also because there is a tendency for people in groups to divide up the emotional territory. If A is going to be angry, B may turn into a soother, C a weeper, and D a checked-out party animal. Don't be surprised then to have one child showing predominantly one kind of behavior, and another predominantly another. It doesn't mean that the angry child feels no sadness, or the sad child no anger. It doesn't mean that the indifferent child is truly not feeling anything. It does mean that, if at all possible, interventions must aim at keeping things from polarizing too far. Pointing out to your children your sense of what is going on, and asking for their suggestions as to what would make them feel better about the situation, is a starting point. Perhaps a few sessions of group counseling will work if you feel you lack the strength to untangle things.

Some Books in Our Collection

For adults

The Grieving Child: A Parent's Guide, by Helen Fitzgerald. The chief source of this newsletter.

The Seasons of Grief: Helping Children Grow Through Loss, by Donna A. Gaffney. Advice from a therapist.

Losing Someone You Love, by Elizabeth Richter. A collection of accounts by young people who have lost someone.

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn and Joan Harrold. Chapters on the cycles of grief.

When a Parent Has Cancer: A Guide to Caring for Your Children, by Wendy Schlessel Harpham. Chapters on facing death and fear of death.

The Loss That is Forever, by Maxine Harris. A study of adult survivors of early orphanhood.

Books for children or teens

Am I Still a Sister? by Alicia M. Sims
Ages 4-8. Girl, about 6-8, copes with death of her baby brother by writing to him in heaven with all her news and thoughts.

Everett Anderson's Goodbye by Lucille Clifton, Ann Grifalconi
Ages: preschool. Child copes with loss of his dad. Verse and big illustrations.

The Fall of Freddie the Leaf: A Story of Life for All Ages by Leo Buscaglia. Ages 4-8. A classic lesson in death.

Forever in My Heart by Jennifer Levine. Ages 4-8. A girl's mom is dying and her dog discusses death with us.

Geranium Morning by E. Sandy Powell. Ages 4-8. For children with guilt feelings. The boy's dad dies in a car crash after the boy begs off going with him; a girl he meets at school has a dying mom and together they work through their feelings.

Grandad Bill's Song by Jane Yolen, Melissa Bay Mathis. Ages 4-8. A boy loses his grandad and goes around asking each family member what they did the day Grandpa died. They respond in verse covering a range of emotion.

I'll Always Love You by Hans Wilhelm. Ages: preschool up to 2nd grade. Boy and dog age together, then dog dies, boy copes.

It Must Hurt a Lot: A Child's Book About Death by Doris Sanford. Ages 4-8. Little boy's dog dies; a playmates grandmother dies. They cope.

Lifetimes: A Beautiful Way to Explain Death to Children by Bryan Mellonie. Ages 4-12. Death in the abstract, through many examples. One Amazon customer finds it the main grieving book she would give to a stricken family. Soothing.

Once Upon a Hopeful Night by Risa Sacks Yaffe, R. Yaffe, Risa S. Yaffe, Troy Cramer. Ages 4-9. Verse explanation of how life will go on securely even though parent dies.

On the Wings of a Butterfly: A Story About Life and Death by Marilyn Maple. Ages 9-12. A dying older child, Lisa, befriends a caterpillar and watches it go through its transformation to butterfly; at her own death, Lisa joins the butterflies in their migration. Amazon customers liked this despite the weird ending and flowery prose.

Remember the Secret by Elisabeth Kubler-Ross, Heather Preston. Ages 5-9. Make believe story of a young girl, young boy and their imaginary playmates who get to make a trip to heaven in their dreams, where everything is wonderful. (It's not called heaven, but God is responsible for it). Because of this Suzy is well prepared psychologically when it turns out Peter dies.

Sad but OK – My Daddy Died Today: A Child's View of Death by Barbara Frisbie Juneau. Ages 8-12. Through the eyes of her nine-year-old daughter, the author shares the events that befell her family during the time the author's husband was faced with a terminal brain tumor.

Saying Good-bye to Grandma by Jane Resh Thomas, Marcia Sewall. Ages 4-9. Seven year old girl goes to grandma's funeral with parents; discovers good family time.

Straight from the Siblings: Another Look at the Rainbow by Gloria Murray, Gerald G. Jamplosky (Editor). Ages 9-12. A group of thirty-four children share their experiences with terminally ill brothers and sisters.

Talking about Death : A Dialogue Between Parent and Child by Earl A. Grollman. Ages: wide range, the read-along is about 5-9. A read-along picture book explaining death to young children with an extensive guide for parents. Includes lists of pertinent

organizations, books, tapes, and films.

I Will Remember You: A Guidebook through Grief for Teens by Laura Dower. Ages: teenage. From Amazon reviewer: Through stirring words by well-known personalities (E.B. White, Emily Dickinson, Rainer Maria Rilke, Dr. Seuss, Mother Teresa, Woody Allen, even Pooh and Piglet!), as well as from fellow teens who have lost a loved one, grieving teens can begin to take comfort that they're not alone.

The Kid's Book About Death and Dying by Eric Rofes. Ages 9 - adolescent. Fourteen children offer facts and advice to give young readers a better understanding of death.

Straight Talk about Death for Teenagers : How to Cope with Losing Someone You Love by Earl A. Grollman. Ages: teenage. An insightful theologian/grief expert suggests that teen grief is often overlooked or minimized. Addressing this gap, he presents just a few on- target, incisive lines on each page - to be read like poetry - on topics such as 'the first days after a death' and 'facing your future.' The occasional humor is not inappropriate.

How It Feels When a Parent Dies, by Jill Krementz. Children remember their own experiences.

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