



Main Office

9221 Ward Parkway, Suite 100
Kansas City, MO 64114
816-363-2600

East Office

14500 E. 42nd Street, Suite 240
Independence, MO 64055
816-468-5700

Kansas Office

10100 W. 87th Street, Suite 100
Overland Park, KS 66212
913-894-8228

Kansas City Hospice House

12000 Wornall Road
Kansas City, MO 64145
816-941-1000

Solace House

8012 State Line Road, Suite 202
Shawnee Mission, KS 66208
913-341-0318



Kansas City Hospice
& Palliative Care

www.kansascityhospice.org

Copyright 2009 © Kansas City Hospice & Palliative Care. All rights reserved.



SAFE PASSAGE

*Talking to Children and Teens
About Serious Illness*



Kansas City Hospice
& Palliative Care



Solace House

Enhancing each day of your life.

OTHER BOOKS IN THE SAFE PASSAGE SERIES

Understanding Grief

When Death Nears: Signs and Symptoms

Decisions About Artificial Foods and Fluids

Simple Facts About the Control of Pain

These booklets are provided by Kansas City Hospice

& Palliative Care as a community service. They can be

downloaded at www.kansascityhospice.org.

For more information, call 816-363-2600.

Contents

- I. A Child's Understanding of Serious Illness
- II. Talking to Children About Serious Illness
- III. Developmental Stages of Children
- IV. Recommended Reading

A CHILD'S UNDERSTANDING OF SERIOUS ILLNESS

Helping a child deal with serious illness can be challenging. Children have neither the life experience nor the intellectual or emotional development needed to understand as adults do. However, as a member of the family, each child should be included, at an appropriate level, in the discussions and activities surrounding the illness of a loved one.

Children's emotional and intellectual development affects their comprehension. Most children understand illness at some level so it's important for them to know what is happening. How can we help them understand? The most important thing is to provide them with honest, age-appropriate information and then listen to their responses.



Explaining how we feel can be helpful. Tell the child that it is normal to be sad when hearing the news about a serious illness, and explain that adults around them may be upset and crying. This also may be a good time to talk about the family's beliefs concerning afterlife.

Each age group requires a different approach discussing illness or loss. (See Developmental Stages of Children on page 8) Remember, each child is unique. One child may seem unfazed by the news, while another will express extreme emotions. Regardless of their reactions, children need to understand the situation if they are to successfully grieve and cope with the illness of a loved one. You can help by beginning the conversation.



TALKING TO CHILDREN ABOUT LIFE-THREATENING ILLNESS

Beginning conversations

Find a time that will be free from interruptions; turn off any electronic devices such as a phone, television, computer, or anything that could possibly become a distraction. Depending on the child's attention span, your conversation may be brief, but it should not be interrupted.

Explain the importance of what you want to say. "I want to talk with you about something very important," is a good introduction to the conversation. Be truthful, honest and do not avoid sharing the difficult realities of the illness in an effort to spare the child natural sadness or pain. This only confuses children and makes the situation even more of a mystery.

Keep in mind that younger children don't have the attention span for in-depth conversations. Don't be disappointed if, after working up the courage to broach the subject, your preschooler asks what's for dinner a minute after you've begun your conversation. Older children may not have much to say either. Give them time to come back later with questions or thoughts when they are ready.

It may be helpful to ask children what they think will happen to their loved one. You can explain the illness, its possible progression and the possibility that the child's loved one may die. Give enough information for the child to understand the severity of the illness.



Ask children if there is anything they want to say to or do for their loved one. Children often have incredible ideas that can make this time very special.

ADDRESSING CHILDREN'S FEARS

Young children who have experienced the illness or death of a loved one often worry that they too will get sick or that their caregiver will. Youngsters of all ages also worry about what will happen to them during the illness or after the death of their loved one. Children need the security of knowing an adult will care for them. Assure them you plan to be there for them and that they won't be left completely alone.

Emphasize that their loved one's illness is not their fault. Use clear, direct explanations of what happened so younger children won't assume their actions or thoughts caused the loved one's illness or death.

INCLUDING CHILDREN DURING ILLNESS

Let them visit, even help you care for their loved one. Including children can help prevent unnecessary fears about future, similar experiences. Children's understanding of a loved one's health issues grows from seeing, doing and participating in the care of that person. Let children know how they can be most helpful during the illness. For example, by spending time with their loved one or sending notes, homemade pictures or other expressions of love, they can have a part in caring for the patient.

FOR A SUDDEN ILLNESS OR DEATH

Because there is no time to prepare or say goodbye, a child may have more difficulty with a sudden illness. Their questions and feelings will begin when you give them the news. Use basic information as you explain what has happened; it is not necessary to include every detail to give them an accurate picture.

Let children know that their feelings are okay and normal. Include them in the visitation and funeral if they are comfortable with attending. Reassure them they will be cared for and let them know that any questions or concerns they have are important to the adults around them.

If they did not have the chance before the death to tell the person who died that they loved them, encourage children to write a letter to the person saying all they wanted to say. The letter may be left in the casket or on the grave. It is helpful for each of us, including children, to express our thoughts and feelings, and it is not too late to do that during or after the funeral.

WHEN A CHILD ASKS QUESTIONS

The child probably will have questions. Answer only what the child is asking. Do not criticize the questions, no matter how simple or unusual they may seem. Be sure the child knows he or she is not at fault. Listen closely to the child and make sure there is an adult available to answer future questions at any time.

This might be the time to teach a child what it means to physically die. Explain that the heart stops, that the person stops breathing and that he or she can no longer talk or feel. Do not describe death as being like sleep as this may prompt the child to develop a fear of sleeping.

Answer as best you can when children ask “why?” No one has all the answers, and an “I don’t know” might be the best and most honest response. Many adults find that explaining their religious beliefs is helpful. Including a local minister, priest, rabbi, imam, or other member of clergy in the discussion is often helpful.

DEVELOPMENTAL STAGES OF CHILDREN

Children three to five years old do not understand the concept of forever. They will see death as temporary or reversible. Still, the separation caused by illness is particularly frightening for children this age. They need reassurance that their emotions are normal and okay.

“Magical thinking” is common at this age, and children may believe their thoughts or actions are somehow connected to illness or death.

By ages six to nine, children begin to understand that death is final, but they think it happens only to other people. Some may be very curious about illness and want details about physical changes that occur. They may think illness is a scary creature or person who takes people away. Or they might fear that death is contagious. Some may continue to believe that their thoughts cause events. They worry about their caregivers’ vulnerability and want reassurance of their own security if those who care for them become sick.



Between ages nine and 12, many children may have experienced the death of a relative or, more often, the loss of a pet. They know death is final and comes to all plants and animals. They may be extremely interested in the physical process of dying, but still they see death as distant from themselves. It is common for children this age to worry about the effects the loss will have on their immediate future. They also may fear that the loss will set them apart as being different from their friends and school peers.

Adolescents are forging their own identities. Most do so by pushing their parents away. Such distancing from family is part of normal separation. The death of a parent at this age can cause confusion and guilt. Death is fascinating, frightening and particularly threatening for adolescents. They don't like anything that makes them feel different from their peers. Losses may make teens feel more childlike and dependent. On the other hand, teenagers may feel they are required to step into an adult role in response to a loss.



The concept of serious illness is often difficult for children to grasp. Serious illness changes lives forever in adults and children alike. Know that such an event may have a lifelong impact and may be an

ongoing issue to address as time passes. How quickly healing occurs is an individual matter. However, children are remarkably resilient and often find comfort in knowing the truth. Providing the tools to cope allows children to move forward as vital members of a recovering family. Take the time to equip yourself so that the emotional road ahead may be as smooth as possible for the children involved.

RECOMMENDED READING

General:

The Feelings Book, Lynda Madison, Pleasant Co. Publications, Middleton, WI: 2002. ISBN: 1-58485-528-2 (ages: 9-13)

The Next Place, Warren Hanson, Waldman House Press, Golden Valley, MN: 1997. ISBN: 0-931674-32-8 (ages 6 to adult)

When Dinosaurs Die, Laurie Krasny Brown & Marc Brown, Little, Brown & Co., Boston: 1996. ISBN: 0-316-10917-7 (ages: 4-12)

Sad Hug, Mad Hug, Happy Hug, Channing L. Bete Co. Item number 58198B-1-95. Call 800-628-7733 (ages: pre-kindergarten to 6)

A Day With Dr. Waddle, Center for Basic Cancer Research, Kansas State University, Manhattan, KS: 1988. (ages: 4-12)

Saying Goodbye to Daddy, Judith Vigna, Albert Whitman & Co., Morton Grove, IL: 1991. ISBN: 0-8075-7253-5 (ages: 4-9)

I Know I Made It Happen, Lynn Bennett Blackburn, Centering Corp., Omaha, NB: 1991. ISBN 1-56123-016-2 (ages: 6-12)

For teenagers:

When Your Brother or Sister Has Cancer: A Guide for Teens, National Cancer Institute, Bethesda, MD: 2005. P222

When Your Parent Has Cancer: A Guide for Teens, National Cancer Institute, Bethesda, MD: 2005. P223

Tear Soup, Pat Schwiebert and Chuck DeKlyen, Grief Watch, Portland, OR: 1999. ISBN: 0-9615197-6-2 (ages 10 to adult)

How It Feels When a Parent Dies, Jill Kremetz, Alfred A. Knopf: NY: 1981. ISBN: 0-394-75854-4

Straight Talk About Death for Teenagers, Earl A. Grollman, Beacon Press, Boston: 1993. ISBN: 0-8070-2501-1

Books for helpers:

When Someone Has a Very Serious Illness, Marge Heegaard, Woodland Press, Minneapolis: 1991. ISBN: 0-9620502-4-5 (ages: 6-12)

What Does That Mean? Harold Ivan Smith and Joy Johnson, Centering Corp, Omaha, NE: 2006. ISBN: 1-56123-196-7

Preparing the Children, Kathy Nussbaum, Gifts of Hope, Kodiak, AK: 1998. ISBN: 0-9665496-0-0

Lean On Me, Doug Manning, In-Sight Books, Oklahoma City, OK: 1998. (for parents or helpers)

150 Facts About Grieving Children, Erin Linn, The Publisher's Mark, Incline Village, NV: 1990. ISBN: 0-9614636-3-5

ABOUT KANSAS CITY HOSPICE & PALLIATIVE CARE

Kansas City Hospice & Palliative Care is a nonprofit organization offering a range of services for people of all ages and at any stage of serious illness. Since 1980, we've been enhancing life for the seriously ill and their families in the greater Kansas City area.

Our programs include:

- Kansas City Hospice, providing comfort and care at home or in a nursing home.
- Palliative Home Care, comfort care for people pursuing curative treatments.
- Carousel, pediatric palliative care.
- Kansas City Palliative Medicine, full-time physicians specializing in comfort care and symptom management.
- Kansas City Hospice House, an inpatient facility offering expert medical and nursing care 24 hours a day in the comfort of a homelike setting.
- Passages, counseling and resources for difficult transitions in life.
- Solace House, a counseling center for grieving children and their families, as well as for individuals.

For more information or to schedule a free assessment to see if one of our programs may be helpful to you, call Kansas City Hospice & Palliative Care at 816-363-2600.

SOLACE HOUSE

Solace House, a counseling center for grieving children and their families, as well as for individuals

www.kansascityhospice.org

